

Independent Assessment Services

Delivered by Atos

Personal Independence Payment (PIP)

Health Condition Insight Reports



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Common Health Conditions: A Guide for Health Professionals

This set of reports has been completed by groups that represent people with specific health conditions and impairments. These groups were asked to provide insights from real life examples to help describe the common issues faced by the people they support.

This is not intended to be a generic 'labelling' of individuals with a condition, but rather an opportunity to provide you, the Health Professional (HP), with some helpful advice about the things that matter in daily life and the everyday challenges which many be faced by people with these conditions.

The aim is that these insights will help ensure that consultations are as effective as possible and that the claimant feels that there is a degree of understanding of the impact on areas of daily life where functional restriction often occurs as a result of the their specific health condition or impairment.

HPs are encouraged to use these reports as a daily reference guide when preparing for assessments, as well as for their own professional development in their role as Disability Assessors.

The content of these reports complements, but does not replace, the HP's own professional clinical training, knowledge, and experience, and their specific training in Disability Assessment and PIP. At all times HPs must ensure that their reports are constructed in line with the DWP's PIP Assessment Guide.

Where any conflict or inconsistency occurs between any guidance or process referred to in these reports and the official documents produced by DWP or Independent Assessment Services, the official guidance or process must always prevail.

I am confident that these reports will provide a rich source of insight and guidance to PIP HPs.

Dr Barrie McKillop, Clinical Director, PIP
[Independent Assessment Services](#)

Amputee

Amputee

Overview of the health condition or disability



What is the condition usually called?

Amputation – can be sub categorised into upper limb or lower limb and multiples thereof – for example, single below elbow amputee or double above knee amputee.

Limb deficiency – for congenital limb loss which can also be sub categorised as above.



What is the generally preferred term when referring to someone with this condition?

Amputee or limb deficient

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

It will be different for each claimant. All areas of daily life mentioned above may have variations on a day to day basis. However, some will experience constant difficulties in some areas.

Temperature and humidity can affect wearing a prosthesis. Residual limb size changes in line with temperature and this can lead to either a too tight socket during hot weather or conversely, to a loose fitting socket in colder weather. Socket fit can become a major problem due to sweating, which in turn can result in the loss of “stiction” or suction in a prosthetic limb socket. This impacts on the fit of the socket and leads to friction sores and also underlying tissue damage.

The socket itself is a major issue for amputees, as a poorly fitting socket means that the limb(s) cannot be worn for extended periods. The discomfort, pain and lack of security may mean that the individual cannot wear their prosthesis safely, repeatedly or reliably. Many people have their amputations due to health issues. The impact of other medical conditions must be taken into account.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

- Walking (indoors and outdoors)
- Moving between floors with different surfaces / heights e.g. carpet to tiled or stepping off kerb
- Standing
- Transferring from seated to standing, bed, toilet, bath, shower and vice versa
- Driving
- Washing, drying and dressing
- Cooking and eating



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Reasons why a claimant cannot or does not wear their prosthesis, such as:

- Sores
- Blisters
- Prosthesis does not fit
- Residual limb size variations (e.g. due to temperature and/or humidity, fluid retention, infection, exercise, weight gain/loss)
- Prosthesis does not work (e.g. component failure)
- Phantom limb pain – Phantom limb pain sufferers experience acute sensations of pain that appear to come from the limb that has been amputated. It is estimated that between 50 and 80 percent of amputees develop phantom limb pain after and amputation. The term ‘phantom’ does not mean that the pain is imaginary. Phantom limb pain is a very real phenomenon which has been confirmed using brain imaging scans to study how signals are transmitted to the brain.
- Limb pain (may be caused by any of the above or neuroma – a cluster of live nerve endings which can vary in size)

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Many claimants will learn to adapt to their amputation or limb deficiency. However they can overestimate their ability to manage a task reliably and to an acceptable standard.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

“A prosthetic limb is a replacement limb” – A prosthetic limb will never and can never replace an existing limb. There is no ‘Swiss army knife’ equivalent in prosthetics – no single prosthesis will allow the wearer to complete every task reliably. Even when fitted with the most advanced limb componentry, the use of a prosthetic limb does not mean that the individual can return to his or her previous life without any further problems.

“A prosthetic limb can be worn every day and all day” – Most amputees find they cannot wear their prosthesis for extended periods without issues (see above under commonly reported variability).

Not every amputee with a prosthetic limb can get about like a Paralympic athlete. Those competing on running blades and high end prosthetic limbs are in the minority and usually otherwise healthy.

A lower limb prosthetic wearer can exert more energy when walking. As an example, an individual with a single above knee prosthetic limb can be expected to exert 65 to 80 percent more effort and energy in walking than an able bodied person. This additional strain can also lead to muscular and postural problems, due partly to compensating for the prosthetic limb(s) itself



How is it best to ask about these areas?

Be open, honest and free of preconceptions. Acknowledge the claimant is the expert in how it feels for them.

Ensure when a claimant says they can manage a task, you consider whether they manage it reliably and ask them further questions to clarify this.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

- prosthetic centre continuing records
- Physiotherapy and/or occupational therapy
- GP (for referrals to specialist services, pain relief and psychological input)
- Pain clinic
- Psychology
- Most importantly – the claimant. They are the specialist in how their disability affects them. But please note: as a lifelong condition, some claimants may have learnt to manage symptoms without medical input by adjusting or limiting aggravating factors. However, they may still not be able to manage tasks reliably.

Presenting symptoms

Can include, but not limited to:

- Difficulty reaching the location (environmental factors such as stairs, walking from the nearest car park/public transport link, doors)
- Muscular or skeletal problems caused by wearing a prosthesis
- Physical or phantom pain
- Blisters/sores affecting residual limb
- Nervousness and body image issues
- Anger (emotionally charged)
- Stoicism (not wanting to admit difficulties, or underplaying these)
- Other health conditions which may be the cause of the amputation e.g. heart condition, diabetes





Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in an Assessment Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Recognise the amputation.

Never assume either:

- They need any assistance
- They won't want any assistance.

Just ask.

Avoid the use of the word 'stump' unless the developed rapport has indicated this is appropriate.

Look – particularly when considering a handshake at the start of the meeting. Do they have a hand to shake? It is ok to shake with left hands if necessary.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Be open and honest. Recognise the amputation.

Identify if a claimant is an armed services veteran. Evidence, which the DWP recognises, shows that veterans (whether an amputee as a result of service or not) have learnt the skills to cope in life and find it difficult to recognise and communicate when their ability to manage day to day life is compromised.



Further reading:

Blesma is a charity which supports armed forces veterans who are amputees. However, there are general leaflets on amputation which includes phantom limb pain, amputation explained and others.

www.blesma.org/how-we-help/prosthetics

NHS website

www.nhs.uk/conditions/amputation/Pages/Introduction.aspx

Anxiety

Anxiety



Overview of the health condition or disability



What is the condition usually called?

Anxiety



Are there any alternate names?

There are no alternative names for anxiety, but there are different types of anxiety disorders that you should be aware of:

- Generalised anxiety disorder (GAD)
- Panic disorder
- Phobias such as social anxiety disorder/social phobia
- Post-traumatic stress disorder (PTSD)
- Obsessive-compulsive disorder (OCD)



What is the generally preferred term when referring to someone with this condition?

Someone experiencing anxiety/someone with an anxiety disorder

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

Anxiety can affect all aspects of daily living. The severity of this may vary; often the same areas of a person's life will be affected, but more or less severely at different times.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

Anxiety can affect all areas of daily life such as personal, social, occupational and physical functioning. People with anxiety may find themselves worrying all the time about things that are part of their everyday life or about things that are unlikely to happen. This worry can cause a range of physical symptoms.

Anxiety can make a person very nervous and tense and cause difficulty concentrating. They may find it difficult to complete personal daily tasks and their family relationships may be affected. They may experience sleep problems, changes in appetite and problems in their sex life. Things that they may find particularly challenging are when they have to make important decisions or when are facing things that may have a big impact on their life (e.g. interview, new job, moving house).

Anxiety can have a significant impact on social functioning, sometimes making it difficult to attend or plan social events. People with particular types of anxiety (such as agoraphobia and social phobia) may struggle to leave the house or participate in everyday social interactions such as having a phone call or meeting someone new.

Impacts on personal, social and physical functioning can make it very difficult to engage with health services – making and attending appointments and leaving the house can cause unbearable levels of anxiety and/or panic. This can affect their ability to access treatment. In some cases people can be embarrassed to talk about the extent of their worries or difficulties for fear of being judged or misunderstood.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

How their anxiety is affecting their social life and their work life. Ask whether they are unable to or find it difficult to carry out routine tasks and daily functioning. Ask if it is affecting their ability to perform as usual at work. Ask whether performing simple or routine tasks has an effect on their wellbeing. Ask if it is affecting their physical health such as digestive problems, chest pain and breathing difficulties.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

They may find it embarrassing to talk about their symptoms and may worry that they will not be taken seriously. Being asked about their symptoms may also trigger their anxiety. They may also underestimate the impact that anxiety is having on their physical health.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

The psychological and physical impact that anxiety can have on an individual can be extremely profound. People may find it difficult to understand and empathise with them, making the individual feel more isolated and withdrawn.



How is it best to ask about these areas?

Take their mental health problem seriously and be understanding and empathetic. Don't just focus on their physical ability to undertake daily activities but how it affects them personally (i.e. anxiety before, during and after the activity).



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

A letter from their GP can convey the impact of anxiety on the individual. They can confirm physical symptoms such as increased heart rate or digestive problems. They can also convey the extent to which anxiety impacts on the individual's daily functioning.



Presenting symptoms

An individual with anxiety can experience both physical and psychological symptoms.

Physical symptoms include: Nausea, tense muscles and headaches, pins and needles, feeling light headed or dizzy, faster breathing, sweating and hot flushes, fast or irregular thumping heartbeat, raised blood pressure, needing the toilet more frequently, churning in the pit of the stomach, panic attacks.

Psychological symptoms: feeling tense, nervous, on edge, having a sense of dread, feeling like the world is speeding up or slowing down, thinking that people are looking because they can tell that you are getting anxious, feeling restless and find it difficult to concentrate.

It is important to be aware that people with anxiety may not have any visible signs or symptoms at all when presenting at a face-to-face assessment.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

People with anxiety can become very tense and anxious in unknown situations where they have little control. It can be useful to brief them on exactly what the consultation involves and what they will be asked to do. You could ask them if there are any adjustments that would make them feel more comfortable during the assessment e.g. ask if they would feel more comfortable if a friend or family member was to come with them or ask if they would prefer to do the assessment in their own home. Offer them breaks if they need it, provide water and tell them where the nearest toilets and exits are.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Include the person in the consultation process by asking them if there is anything that you can do to make them feel more comfortable. Let them know what to expect from the process. Ask them if they have any initial concerns about the consultation and see if you can address this. Be understanding, empathetic, patient and try not to put the individual under any pressure. Encourage them to take their time. Be aware of the person becoming more anxious and let them know that they can have a break at any time. Also be prepared for what you would do if the consultation were to trigger extreme anxiety and the individual were to become extremely nervous, tense and experienced physical symptoms such as feeling sick, light headed or finding it difficult to breathe.



Further reading:

www.mind.org.uk/information-support/types-of-mental-health-problems/anxiety-and-panic-attacks/#.WDgrHn2gXps

Autism

Autism



Overview of the health condition or disability



What is the condition usually called?

Autism



Are there any alternate names?

- Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC)
- Classic Autism (known as Kanner autism)
- Pervasive Developmental Disorder (PDD) or High Functioning Autism (HFA)

Asperger Syndrome is a form of autism. High Functioning Autism is often used interchangeably with Asperger Syndrome.



What is the generally preferred term when referring to someone with this condition?

Autistic

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

Because of the range of cognitive functioning among autistic people, there is major variation in the way these impairments present clinically. For some autistic people, their impairment will mean they face difficulties in many PIP daily living activities and mobility. Problems with executive function will mean that very often people will need some degree of help (prompting, supervision or practical help) with the day to day tasks in activities 1 – 6 and 10. Autistic people will be likely to have problems with social engagement, as laid out in activity 9.

Autistic people will present differently according to the environment they find themselves in: it is effectively an inherent part of the condition. While a person may be able to manage something in one environment they may not be able to do it in another. And the person may not have an awareness of this. For example, someone may be able to talk about managing money, for example doing the maths of checking their change in an interview in an office, but in a real situation, with associated social pressures and sensory stimulation, they may not manage it at all. Stressors, which may vary for individuals (e.g., level of noise, light sensitivity, anxiety, unexpected change of routine, work deadlines), can affect daily functioning on a day to day basis. These stressors can lead to anxiety and mental health problems.

Some people have had such bad experiences in the past that they are not able to leave their home or interact with people outside their immediate family. In such cases, attending an assessment centre may not be feasible and a home consultation may be appropriate.

This is why, in most cases, it is extremely important to talk to a family member, advocate or someone else who knows the person well to gain a complete understanding of the impact a claimant's condition has on their day-to-day functioning. This is a standard part of autism diagnostic assessments, as is observation of the individual's functioning within different environments due to the fact that while a person with autism may be able to manage something in one environment, they may not be able to do it in another.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

The behaviours associated with autism arise in three distinct areas, known as the triad of impairments. These are social communication, social interaction and social imagination, which are shared by all people on the spectrum, irrespective of their intellectual capabilities. From a psychological perspective, these are the result of difficulties with executive function (processing of information), central coherence (being able to build an overall picture from detailed information) and mentalising (thinking of situations beyond one's experience, including understanding another person's perspective). In addition, the vast majority of autistic people have sensory under-or over sensitivities, which can have a very disabling impact on their lives. Although not an inherent part of the condition, most autistic people have high levels of anxiety as a result of their impairments.

All autistic people have problems with social interaction. Many people are unable to identify the specific difficulties they have because they do not know what is required of them within a particular situation and so cannot state how they fail to meet those requirements. In other words, one requires an understanding of social interaction to identify and report where one is failing to interact in a socially appropriate way. While some autistic people will have a more general understanding that they have difficulties with social interaction, some people will have no insight into their difficulties at all. Autistic people generally speak the truth as they see it from their perspective.

Because autistic people have difficulties with social interaction, they may try to meet perceived social expectations in unpredictable ways, and especially in ways they think the person speaking to them wants to hear. For example, it is common for autistic people to try to give the answer they think is expected of them, such as agreeing that they understand something, when in fact they do not. Anxiety and sensory stimulation also play a major role in how well someone is able to manage in different situations.

All autistic people also have difficulties with social communication. As a result, even if they can identify some of the difficulties they experience, they may find it difficult to put this into words. They may have difficulties with either expressive language, receptive language, or both. Some autistic people are not able to use verbal language at all or only in very limited ways.

Comprehension levels in particular are often significantly below intellectual and expressive abilities. Therefore, many autistic people initially present as able and the impairments they experience are masked. This can lead to significant difficulties on a day-to-day level, as people expect them to understand much more than they are actually able to.

This is exacerbated as **autistic people have deficits in social imagination.** They lack the ability to predict a range of possible consequences arising from past and present events. They struggle with being able to foresee the consequences, in social, and practical terms of their own and others' actions, and to act appropriately on this knowledge. They often have problems in coping with even apparently simple social demands of everyday life and often the practical aspects of life. They cannot think about situations that they have not directly experienced. They cannot hypothesise about different scenarios.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

There will be variability in cognitive functioning among autistic people and how their impairment will present, although as stated above, the characteristics are generally divided into three main groups – social communication, social interaction and social imagination. The health professional will need to focus on difficulties faced by autistic people, the stresses these difficulties may cause and the extent that this will impact on their day to day functioning, especially if there is a cumulative effect that can lead to anxiety and mental health problems. These difficulties will centre around:



- non-verbal communication - an autistic person may have difficulty understanding and interpreting non-verbal communication, making it hard to understand the message someone is trying to communicate;
- language and its interpretation - an autistic person may take a statement literally, making it hard to follow conversations or understand instructions;
- unwritten social rules - an autistic person will find it difficult to work out these rules and conversation can become a complicated and stressful process;
- physical boundaries - an autistic person may find it difficult to navigate complex rules about physical boundaries such as appropriate contact or distance;
- empathy - difficulty with identifying non-verbal clues can make it hard for autistic people to work out how someone is feeling;
- change – many autistic people will experience high levels of stress and anxiety around change, especially if it is unexpected, and will have a strong need for routine and structure;
- hypothetical thinking – some autistic people may find it difficult to think hypothetically, affecting their ability to plan or prioritise work;
- single focus – many autistic people describe having ‘single focus’ attention, making it difficult to multi-task;
- sensory sensitivity – autistic people can be over or under sensitive in any or all seven senses (sight, sound, touch, taste, smell, balance, body awareness) and can have an impact on an autistic person’s ability to concentrate;
- executive functioning – the mental processes involved in skills such as planning, organising, sustained focus etc.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Many autistic people will lack insight into their condition. It is rare that one can rely on self-reporting to gain an accurate picture of the autistic claimant’s difficulties. Unless someone on the autism spectrum has additional medical conditions, they may have very little contact with medical professionals, and understanding of autism among the medical community is generally much lower than it needs to be. If someone has received their diagnosis within the last few years, they may have access to a diagnostic report. Unfortunately, all too often diagnostic reports do not meet good practice in providing a full picture of a person’s strengths and difficulties.

Eliciting accurate and useful information from an autistic person may be difficult due to problems with social communication. An autistic person may take a literal interpretation of language used in the face-to-face consultation. Because of difficulties with flexibility of thought, an autistic person may not be able to think hypothetically. Consequently an autistic person may not know how to answer a question or provide a relevant or detailed response. In a face-to-face consultation, it is important to take this into account and use other supplementary information.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Autism is often described as a hidden disability as autistic people do not look disabled and behaviours can be difficult to see. Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all autistic people share certain difficulties, their condition will affect them in different ways. Autistic people may experience over or under sensitivity to sounds, touch, tastes, smells, light or colours. Some autistic people may have difficulty with executive function – the mental processes involved in skills such as planning, organising, sustained attention and multi-tasking. Living in a world where most people experience and interact with it differently from you can be very confusing and challenging. That’s why most autistic people find it hard to understand other people, and often find themselves misunderstood.



How is it best to ask about these areas?

Ask specific, explicit and clear questions. And ask supplementary questions and prompts.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

The most common source of additional evidence sought as part of the face-to-face assessment is the person's GP. This reflects the weighting towards a medical model of disability in the system. Many autistic people will lack insight into their condition. It is extremely rare that one can rely on self-reporting to gain an accurate picture of the claimant with autism's difficulties. Autistic people with a learning disability are often not ill and may not see their GP for extended periods. They may also find it hard to access primary care services due to a lack of reasonable adjustments and continued low levels of understanding of autism among health professionals.

Unless someone on the autism spectrum has additional medical conditions, they may have very little contact with medical professionals, and understanding of autism among the medical community is generally much lower than it needs to be. If someone has received their diagnosis within the last few years, they may have access to a diagnostic report. Unfortunately, all too often diagnostic reports do not meet good practice in providing a full picture of a person's strengths and difficulties.

In terms of additional expert evidence, psychologists' reports may be available as part of the diagnostic process or other mental health assessments. These should provide a picture of the individual's functioning from a psychological perspective. Some individuals may have speech and language therapy or occupational therapy reports, which would present evidence about communication, social and sensory needs. A good social care assessment should set out a person's needs in relation to everyday functioning and activities. Education Health and Care Plans/statements can also provide useful information. An employment support report would set out evidence about functioning in relation to seeking and finding employment. Other professionals supporting people on the spectrum, such as mentors, befrienders, co-ordinators of social groups, may be able to provide relevant information about the challenges someone faces with social functioning.



Presenting symptoms

Autistic people have a propensity to interpret questions literally and give responses they think will please the health professional. They may need extra time to take in information and respond to people. Autistic people's senses are often extremely sensitive to noise, light, smell or colour. They can become anxious and stressed in the face-face consultation, especially as it may reflect a change of environment or routine, or if they are having trouble processing information or if they are experiencing sensory overload. They might act in a repetitive way, tapping or flapping their hands or pacing around, and when things get too much, it can lead to uncontrollable meltdowns. They may shout, cry, physically lash out or close down. In such a circumstance, it is best to find a quiet, uncrowded space and wait for it to pass.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Ask them if they have any special needs and how you can support them. For example, an autistic person might be sensitive to bright lights or background noise. So, ask them if the room is comfortable and whether there are any changes that need to be made (e.g., dimming lights).

Take note of any adjustments around pace of the consultation to make sure that an autistic person is not being overwhelmed with too many questions too quickly.

If they bring someone to assist the autistic person, if necessary, ask them if there is anything else the health professional can do to make the autistic person feel calm and in a safe place.



Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Provide clear information about the face-to-face consultation beforehand and send out any documents in well in advance so that an autistic person has time to process all information, including information about the venue, the time and date, the purpose of the consultation, who they can bring and any other relevant information. Make sure they know who to contact if they have any further questions or need more information.

Allowing them to visit the venue in advance can help an autistic person to understand where they will be going and to familiarise themselves with the venue. It may also provide an opportunity for them to let you know in advance of any adjustments that may be needed.

At the face-to-face consultation, autistic people may need a range of adjustments because of their difficulties in communication, literal interpretation of questions, possible hypersensitivity to sensory stimuli, and anxiety.

Provide clear information about what is expected in the face to face consultation and, as they may need extra time to take in and process information, providing questions in advance that are easy to read and making sure they have more time to process the questions in the interview may be useful.

Ask specific questions. And ask supplementary questions and prompts but use clear, literal language and avoid using jargon.

People with autism often have a very literal and concrete understanding of language. If a message is not clear, then misunderstandings will arise. For example, “can you sit down?” questions whether you are capable of sitting, and is not an invitation to sit.

Allow enough time for the meeting to go at a manageable pace and check that people are able to keep up. You may need to allow time for autistic people to process information or for supplementary questions.

Cystic fibrosis (CF)

Cystic fibrosis (CF)



Overview of the health condition or disability



What is the condition usually called?

Cystic fibrosis (CF)



Are there any alternate names?

- CF
- Mucoviscidosis



What is the generally preferred term when referring to someone with this condition?

Person with cystic fibrosis (CF)

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes

In addition to the description of variability above, please note: CF is a progressive condition, which presents worsened symptoms and increased treatment burden. The nature of CF means there is an inherent inability to predict and plan for fluctuations in future health status.



What aspects of daily living can be worse and what might be constant?

Help needed with cooking, nutrition and carrying out treatment 'to an acceptable standard' could be constant. Difficulties with aspects of personal care/moving around may be worse at times of infection, IV treatment or exacerbations; although some people with physical difficulties moving or exertion may struggle with these constantly too.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

All people with CF have daily life disrupted by frequent hospital appointments, inpatient stays, being unwell and fatigued, which can last for days, weeks or months. This negatively impacts an individual's educational and employment opportunities and pathways to an independent life. Cystic fibrosis (CF) is a condition that varies on a daily basis and continually deteriorates an individual's health over their lifetime.

It is of paramount importance that people with CF are given timely support in maintaining their treatment routine to combat the progression of the condition to a critical stage.

When an individual has an exacerbation of their symptoms or lung capacity is low, everyday tasks are challenging. This often necessitates the support of a carer, partner or family member.

The treatment burden of daily medications, nebulisers and extensive physiotherapy, combined with restricted lung function and a reduced capacity to absorb nutrients, render the individual fatigued, to a greater or lesser extent, on a daily basis. The logistical challenges and pressure for individuals to be responsible for and maintain their own extensive and complex treatment routine directly impacts quality of life. Individuals may be required to self-administer intravenous (IV) treatments at home and monitor their own condition.

The nature of CF care and treatment has significant logistical and financial implications that include a heavy burden of travel to a specialist regional centre or clinic, difficulties gaining insurance for travel and critical illness cover. Stress, anxiety, low self-esteem, feelings of isolation and depression are all elements of an individual's condition that must be monitored and managed.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Using open questions to establish what support is given and needed and what would happen without this, or asking what could be achieved better with some help.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

People with CF are segregated from one another due to an inherent risk of passing the infections individuals carry between one another – this is known as cross-infection.

Individuals with CF require a high calorie diet as they struggle to absorb nutrients. Individuals with CF are often underweight and must supplement their diet with specially formulated drinks, shakes and yogurts, and often overnight feeds to keep weight up. These are usually administered via a tube into the stomach.

Nutritional and digestive problems prompted by the disease lead to a variety of condition complications.

Some people with CF (particularly teenagers) may find it difficult to be frank about any difficulties with continence. They may feel embarrassed discussing this openly.

As patients reach their teens and twenties, insulin production can become deficient due to pancreatic disease which can lead to individuals CF-related diabetes mellitus.

People with CF are prone to developing bone disease (thin, brittle bones). This is exacerbated by the adverse effects of some steroidal treatments for controlling lung disease. This is not visible, but can make people frailer and more anxious and can cause additional factors to consider when they are managing travel and daily life.

Those that develop other associated medical conditions then have the challenge of managing, in its entirety, the symptoms of this second health condition which in itself presents numerous difficulties and a different type of treatment.

CF can cause fertility issues. In most men with CF, the tubes carrying sperm are blocked, causing infertility. In women, associated weight issues mean that menstrual cycles are disrupted and irregular, affecting fertility. Again, younger people may find this hard to express and openly discuss, and may not have come to terms with what this means for their future life choices.

Exercise is a critical element of the treatment programme for people with CF. This means that many people with CF will be pursuing an active lifestyle and may even be taking part in competitive sports and activities. This is not necessarily an indication of independent living or good health.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Many people report to us that it is rarely understood how much preventative work and risk management is involved around contracting very dangerous and damaging infections. Once lung tissue is damaged, it cannot be repaired and infections cause decline in respiratory function and overall health. Young people may feel that they cannot demonstrate the importance of parental support which keeps their hospital admissions to a minimum.

Many people need a significant amount of support if they are to be able to study or work, as the burden of treatment takes them a considerable amount of time, and can prevent them from doing normal activities. There can seldom be any time left to cook properly.

Those who live alone may find it hard to admit that they would be able to cope better with their dietary requirements (nutrition needs) and treatment regime if they had more support.

If diet and treatments are compromised, then health can decline very soon afterwards.

Many young people report that although they have good insight into their dietary requirements and the treatment regime, they find it hard, due to fatigue and motivation, to keep these up to an acceptable standard.



How is it best to ask about these areas?

Using open questions to establish what support is given and needed and what would happen without this, or asking what could be achieved better with some help.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Due to the complexity of cystic fibrosis, those with the condition will be under the care of a specialist multi-disciplinary team and as such, a range of evidence from the consultant, nurse, physiotherapist, dietician and psychologist is likely to be relevant, but this will vary between people with cystic fibrosis depending on their individual condition.

As a key point of contact, it would be useful to obtain evidence from the individual's CF Nurse or CF Specialist social worker, as they will have access to records from other professionals in the multi-disciplinary team including a psycho-social understanding of their patient.

Presenting symptoms



A person with CF may present with frequent and intense episodes of coughing. This is not infectious, but a person should be given some time to recover.

Generally a person with CF can look healthy and their difficulties with Daily Living and Mobility may not be apparent. It is therefore vital to gain an understanding of their condition by encouraging an open and frank discussion and looking beyond the appearance.

Etiquette and common courtesies



It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

- Please consider the information about coughing given above.
- Shaking hands may not be appropriate due to infection risk.
- Please consider that if the assessor has a cold or cough, that this poses an unacceptable and serious risk to the person with CF, who does not have the same defence mechanism to expel harmful bacteria. The bacteria could adversely affect someone's health, lead to lung damage and even death.
- A person with CF may consider being called a 'sufferer' inappropriate, given that this is a genetic, serious and life-limiting condition.
- Due to the risk of cross infection, although a relatively small one, a peak flow examination should never be carried out on someone with Cystic Fibrosis'.



Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

All standard communication methods are appropriate.

In relation to a coughing episode, it would be helpful if the assessor does not panic, or fuss, but offer a glass of water and some time for them to 'catch their breath'. Intervention would only be necessary if the coughing was prolonged or interfering with breathing.



Further reading:

Page 10 of the Full Registry Report 2015

www.cysticfibrosis.org.uk/the-work-we-do/uk-cf-registry/reporting-and-resources

For more general information:

[https://www.cysticfibrosis.org.uk/what-is-cystic-fibrosis/faqs#Is cystic fibrosis known by any other name?](https://www.cysticfibrosis.org.uk/what-is-cystic-fibrosis/faqs#Is%20cystic%20fibrosis%20known%20by%20any%20other%20name?)

Deafblindness

Deafblindness



Overview of the health condition or disability



What is the condition usually called?

Deafblindness



Are there any alternate names?

- Dual sensory impairment
- Multisensory impairment



What is the generally preferred term when referring to someone with this condition?

Deafblindness

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

As highlighted, there can often be variation in the ability of someone to use the senses they have left in different environmental conditions. Some people will struggle to see anything in darker or very bright environments. People with hearing impairments, who use hearing aids may be able to have one-to-one conversation in a quiet room but will struggle to hear speech in a room with background noises or when outside. Therefore it is important to consider how person's ability to see and hear might vary in different environments.

For people with Usher Syndrome, a genetic condition that causes deafblindness, sight can vary significantly given the time of day. Some people with Usher Syndrome experience night-blindness and this impacts daily activities more so in the Winter for example, when it gets darker much earlier. This must be explored with the individual.

It should be noted that for some deafblind people, they may experience deterioration over time: certain genetic conditions that cause deafblindness can get progressively worse, such as Usher Syndrome and CHARGE.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

The combined effect of vision and hearing impairment can have significant impact on a person's ability to carry out daily living activities and on their mobility. The impact will vary depending on the degree of impairment, age, skills person has in using their residual vision and hearing and the earning opportunities a person has had. For instance, factors such as whether a person has congenital (from birth) or acquired deafblindness will have significant impact on their functional abilities. In particular, deafblindness will have an impact on 3 areas of functional ability:

Communication:

Although communication needs of deafblind people are complex and varied, it is important to note that deafblindness can have an impact on person's ability to use certain communication methods. For instance when a deaf person might be able to lip-read, a deafblind person might not or could only do it in certain lighting or at a certain distance. When the ability of a deafblind person to communicate is assessed, it is important to remember that many deafblind people may not be able to use standard modes of communication, and even those who do, may not be able to do this repeatedly, reliably and safely, especially in busy workplace environments.





Access to information:

Deafblind people are less able to compensate loss of one sense with another, and therefore will use other senses such as touch, body awareness in space, balance, smell or taste to get the information. Many deafblind people will need assistive technology or aids to access written information and some will require human support.

Mobility:

Deafblindness has significant impact on mobility. Sight and hearing are the two distance senses which are important for person's ability to navigate around safely. Deafblind people are not able to compensate an impairment of one sense by greater reliance on the other.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Health Professionals should ask about the potential impact of the external environment on communication and mobility – for example, the impact of different lighting on being able to lip read, or noises that may interfere with hearing aids when outside. Asking questions such as how the individual copes in unfamiliar locations in terms of navigating or communication can reveal how much support someone actually needs.

Mobility is particularly important, and the ability of someone to navigate externally must be explored in depth.

Variability of the condition should also be asked about specifically, especially for people who experience night blindness.

Health Professionals should always be asking whether something can be done reliably, repeatedly and safely – just because it may seem a person who is deafblind can hear well in an assessment room (which is an artificial environment) this will often not be the case in different environments. It is not always true that how the person is on the day of the assessment is representative, and this must be explored in more detail, particularly regarding variability.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Many disabled people prefer to talk about their abilities and the ways they cope, and this can mask the ways in which they struggle. For deafblind people, communication/engagement and mobility are areas where issues are likely to be understated, especially the details of variability. These are also areas where issues may not always be apparent without further questioning; for example, in a face-to-face assessment in the home, an individual may seem comfortable navigating and independently carrying out tasks, but the consideration of whether this is due to familiarity must be taken into account. In particular, coping in unfamiliar situations should be explored.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

With some deafblind people, particularly those with Usher Syndrome, it is difficult to see the disability at first impression. For example, people with Usher Syndrome often do not look blind and often articulate well, especially where deafness has been acquired in teenage years (it is a progressive condition). Thus it is important to properly explore how people carry out daily activities and ways they may struggle – especially in unfamiliar situations.

Similarly, the variability and impact of hearing loss and vision loss can often be misunderstood.

Deafblind people will generally struggle with localisation of sound, may not be able to hear sound at a certain pitch and won't be able to rely on cues from environmental noises; equally they won't be able to safely compensate for this by using visual cues. When a person's ability to navigate around is assessed, it should be taken into account that the ability to hear speech is not always an indicator of a person's ability to distinguish environmental noises. Hearing aids are not as helpful with environmental noises as they are with speech.

Equally visual acuity alone is not an indicator of how much a person could rely on their vision to navigate around safely. Visual field, light sensitivity and other factors should be considered as well, some deafblind people use mobility aids, such as red and white canes or guide dogs, when others will require human support to navigate around. The difference in impact of visual field and visual acuity should not be confused. An individual might have good visual acuity, and so can see an object presented in front of them, but they may have loss of peripheral vision, which can make travelling dangerous (for example, if they cannot see things on the floor in front of them). However it would be easy to assume that if you show someone an object and they can see it, that they do not have issues with their sight in other ways.

If vision and hearing impairments are considered separately a person's ability to navigate around could easily be overestimated.



How is it best to ask about these areas?

In each area, the Health Professional should ask if the task can be done reliably, repeatedly, and safely, and in what circumstances this would not be the case. For example, if a test is carried out for vision and the individual can see the object, the Health Professional should ask if there are situations where they would not be able to see the object (if it is on the floor, if it is further away, etc.).

It is important to ask the deafblind person to explain in which situations they may struggle most with communication/engaging, access to information and mobility.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Medical reports from specialists, such as audiologists, are more thorough but they are not always easy to interpret or understand. We would recommend asking specialists to provide evidence of the impact of the condition on PIP functions.

Presenting symptoms

These vary very widely from person to person for deafblindness.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

If a deafblind person needs to wait for their assessment, they may need assistance getting to a seat. They should be asked if they require any help.

Assessors should be mindful that when they call a deafblind person for their assessment, they may not hear their name has been called or be able to see which room they need to go to for the assessment. Particularly if they do not have support with them, guidance and assistance should be offered at this stage. Similarly, it should be offered when leaving the assessment room.

When a deafblind person attends an assessment with communication support, the Health Professional should be talking to the deafblind person, rather than their interpreter/communication support. Asking the deafblind person how best to support this, e.g. in terms of lighting or positioning in the room, is best practice.

Health Professionals should not assume abilities based on physical impressions – they should always ask what the experience of the individual has been, and whether this varies in different circumstances.



Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Deafblind people use many different methods of communication. The method, or methods used will depend on the amount of residual sight and hearing and any additional disabilities the individual has. It will also depend on whether the individual has learned formal language before becoming deafblind. It is important to make sure a person is given the opportunity to describe what their needs are before the assessment. Some deafblind people will require interpreters with additional skills, which can include British Sign Language interpreters who use visual frame or hands- on BSL or deafblind manual interpreters. Some will be able to lip-read, but might require good lighting and to sit right opposite the person who is speaking or be closer to them to be able to see. Other people will be able to use clear speech.

Congenitally (from birth) deafblind people might use picture systems, objects of reference or other individualised methods of communication.

Further reading:



Sense provides a number of resources for information on different aspects of deafblindness. These can be found here:

www.sense.org.uk/content/about-deafblindness

We would recommend focusing on the resources in the sections titled Types and conditions, Communication and Providing a good customer service to deafblind people.

Deafness

Deafness



Overview of the health condition or disability



What is the condition usually called?

Deafness



Are there any alternate names?

- Hearing loss
- Hearing impairment
- Partially hearing



What is the generally preferred term when referring to someone with this condition?

Depends on the individual, for example a young adult who was born deaf may not feel they have “lost” anything and that “hearing loss” does not feel appropriate to them. Someone who has become deaf may feel “hearing loss” is appropriate. “Impairment” may be viewed negatively by some individuals.

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

The impact of deafness on daily living and tasks can be highly variable depending on context which includes acoustic and lighting conditions, deaf awareness of others, use and benefit from hearing aids or implantable devices, and cognitive/developmental level of the individual etc. The assessing healthcare professional should not rely on their ‘medical knowledge’ or assumptions about the effects of hearing aids or cochlear implants. They should be aware that they will be meeting the deaf person in ideal listening conditions, which are unlikely to be replicated in the deaf person’s daily life. They should not make recommendations that are based solely on their

observations of the deaf person’s perceived communication ability in the ideal environment of the assessment room. They should also bear in mind that unless stated to the contrary, any audiology assessments will have been carried out in soundproof rooms using single pure tones and not complex frequency signals such as speech. A deaf person will not be in such conditions their daily life.

Hearing aids and cochlear implants do not restore normal hearing. Hearing aids amplify sound, which can improve the wearer’s ability to hear one-to-one conversation well. In a quiet environment like the PIP assessment room, they may be very beneficial. However, most speech is heard in background noise and hearing instruments will pick up all sounds including that background noise. The human ear and brain are usually able to focus on a specific sound (such as one voice in a conversation) while screening out unwanted sound (such as other conversations going on in the background, environmental noise, echoes in a resonant environment etc). Hearing instruments are unable to discriminate between speech frequencies of an individual voice the wearer wishes to listen to, from speech frequencies in the nearby environment. In an environment with background noise hearing instruments are far less beneficial and may even make it harder for the deaf person to understand speech.

Hearing aids and cochlear implants use microphones which pick up sound optimally at a distance of 2-3 metres. Beyond this the sound perceived through them is less effective and may be distorted if it has bounced off surfaces before reaching the deaf person. Microphones are often programmed to pick up sound from the front in preference to sounds from the side or behind.

The deaf person is very likely to rely on lip reading to supplement the limited sound they receive. Lip reading is not like reading a book: it is a form of educated guesswork. The ability to lip read varies greatly from person to person, and it relies on the deaf person having good levels of understanding of spoken language, vocabulary and understanding the context of the conversation to be able to work out what the speaker is saying. Different words will have the same lip patterns, eg ‘peach/beach’. The same words may have different lip patterns on different speakers, especially if they have a different accent. The deaf person may find it relatively easy to lip read a person they know well but find it much harder or impossible to understand a stranger. People often obscure their lip patterns by putting their hand in front of their mouth, eating, drinking and chewing gum. The speaker may have a beard or moustache which obscures their lip patterns. People often turn away when speaking, making it impossible to read their lips.



The speaker must be in good light and be face to face with eye contact with the deaf person for the deaf person to be able to lip read them.

Adults who experience loss of hearing during adulthood are able to fill in gaps in information heard (for example when sound quality is poor) so that it makes sense. Adults who have lost their hearing are often able to fill in specific speech sounds even though they aren't actually heard because they have the vocabulary, context and mature processing skills to enable this. Adults who have been deaf since childhood are less able to do this.

If they miss part of the conversation or if the topic changes without warning it can be very difficult for them to catch up. They may lose track completely and give up.

Deaf people are likely to have difficulty with group conversations. In a group conversation more than one person may speak at once. The speaker may be sideways on to the deaf person, making it difficult for them to both hear and lip read the speaker. As speakers change, the deaf person has to work out who the new speaker is, turn their visual attention to them and adjust to reading their lip patterns. By the time they have done this they may have missed the beginning of what the new speaker is saying, making it harder to make sense of what they are saying. It is harder for the speakers to pick up that the deaf person is being left behind in a group conversation.

Deaf people may well need the support of a person familiar to them to support them in the above situations, for example by filling in gaps and repeating parts of the conversation they have missed and by ensuring that they are not left out of the conversation.

The assessment is normally carried out in a quiet room, one to one, face to face with full access to lip reading. The deaf person will have some idea of the context of the assessment. The assessor will therefore be seeing the deaf person's verbal communication in ideal listening conditions. They must ensure that they find out about what the person's communication needs are in their normal daily life. They should ask the deaf person questions about the effects of the barriers listed above. When requesting further evidence, they should also request speech discrimination tests carried out in background noise from the customer's audiologist. Whilst these tests also have limitations when comparing them to everyday situations, they will demonstrate a stark contrast in understanding words and sentences in more typical everyday noise if the individual struggles in these situations.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

Deaf people may find any of the following difficult:

- Verbal communication – because of voice quality leading to difficulties being understood, difficulties hearing speech or understanding accents, or delays in language development etc,
- Engaging with other people face to face - because of communication difficulties and lack of opportunity leading to lack of confidence
- Reading and understanding signs, symbols and words – if their first language is British Sign Language or if they have language or vocabulary delay
- Making budgeting decisions – if their first language is British Sign Language or if they have language or vocabulary delay so have difficulty understanding written bills, terms and conditions etc.
- Washing and bathing – they may not be able to carry out this activity safely without supervision if they are unable to hear a smoke alarm or other warning of an emergency. NB: hearing aids and cochlear implant users will have to remove all external parts when bathing or showering because they must not get wet.
- Preparing food – if they cannot hear timer alarms or cannot read recipes/ packet instructions/microwave instructions etc.
- Planning and following a journey, if they have difficulty judging the speed and direction of traffic sounds.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

All of the above.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Individuals who were born deaf or deafened early in life may have no or very limited understanding of what they miss in terms of hearing levels, listening experiences, or in conversation. Crudely, they do not know what they have not heard. This may mean that they feel they manage fine. The deaf young person is likely to have experienced hearing people being impatient or excluding them from conversations because they cannot keep up. Deaf young people are often bullied over their deafness. Consequently young people may find it particularly difficult to talk about their difficulties. Deafness is not always a visible disability, particularly if the person covers their aids with hair or clothing. Many deaf young people develop skills in appearing to hear and giving the answers they think people are expecting because they do not want to appear different. The assessor should ensure at all times that the deaf young person has understood their questions. They should avoid asking closed questions such as “Did you understand me?”



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

That hearing aids and cochlear implants do **not** restore normal hearing.

Deaf adults have frequently missed out on incidental learning. Incidental learning happens through “overhearing” when children listen to speech that is not directed at them. Very young children learn approximately 90% of the information they acquire incidentally. Deaf children who only hear what someone directly in front of them is saying is only getting about 10 or 15% of the information that they need to learn. Overhearing helps build vocabulary and gives children grammar. Overhearing also gives children general knowledge from the wider world around them. Overhearing is also important in play and socialising. Implications for deaf adults are that they may have reduced vocabularies, may have formed fewer relationships, may be less confident about communicating with strangers, and have less experience of everyday situations etc.

Children deaf from infancy need far more input to learn language and often have serious delays in language and vocabulary. This can have an impact on their understanding of concepts such as time and mathematical calculations.

Consistent evidence from research studies between 1980 and 2000 indicates that deaf children lag behind hearing peers (by 2 to 3.5 years) in mathematics. A 2005 study (Swanwick, Oddy & Roper) explored the reasons for this persistent underachievement by focusing on results from the National Mathematics tests taken in the UK by all 14 year olds. Findings from the project led to preliminary conclusions regarding the range of national test entry levels for deaf pupils, the types of linguistic issues they encounter, the learning strengths they demonstrate and their experience of mathematics curriculum provision. The concluding analysis raises significant questions about deaf pupils' access to mathematics educational provision and more specifically about the deaf experience of mathematics learning and how they perceive themselves as mathematicians. This can mean that they have delayed maths skills when older.

Deaf children may have difficulty with reading if they have delayed language and vocabulary. Research (Herman, Roy & Kyle, 2014) has confirmed the link between deafness and poor reading levels in many deaf children: ‘Because of their hearing loss, deaf children have difficulty hearing the speech sounds that make up spoken language (i.e. phonology), upon which written language is based. Although many rely on lip-reading (or speech reading) to support their understanding of spoken language, this is only partially successful. In addition, deaf children often struggle to understand language that is not specifically addressed to them and therefore cannot benefit from incidental learning. As a consequence of their impoverished input, deaf children can have speech that is difficult to understand and levels of language and literacy development markedly below their hearing classmates, despite a normal range of intelligence. A variety of factors, such as when deafness was identified, the degree of deafness, the benefit obtained from hearing aids or cochlear implants, the preferred form of communication, etc., contribute to further differences among deaf children... significant gaps in reading levels between deaf and hearing children are still reported for a large proportion of deaf children, gaps which widen as children get older.’

Deaf people whose first language is British Sign Language may well have difficulties with verbal communication, reading and budgeting. British Sign Language is a complete language in its own right and has a different syntax to English so that the word order of sentences differs. Many words used in English do not exist in BSL. Many signs used in BSL do not translate directly into English. Where BSL is the individual's first language, English may have been taught as a second language and may not be as fluent.

Listening is a learned skill which takes attention, focus and energy. This means that listening is physically exhausting for deaf people relying on hearing with hearing aids and implantable devices. Whilst they may manage extremely well in the one-to-one interview environment, this does not take account for energy levels in the real world activities. It is much more of an effort for them to listen and interact for longer periods.

People with unilateral loss may face difficulties distinguishing sound in noise because the brain uses differences between the sounds picked up by both ears to filter background noise. They may also have difficulty working out the direction a sound is coming from so may be more vulnerable to traffic.



How is it best to ask about these areas?

Directly, with open questions, followed by more probing ones. Ask the deaf person to explain whether they can always hear and understand as well as they do in the assessment room. Ask them to give examples of situations where they cannot, that occur regularly in their daily life. Ask if they associate mainly with other deaf people.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Evidence from a Teacher of the Deaf and audiologist. The Teacher of the Deaf will have the most direct experience and understanding of a young person's life. The audiologist will need to be asked how the deaf person would function in the real world, not just in a soundproof room in the hospital.



Presenting symptoms

Difficulty hearing or understanding - but absence of this in the ideal listening conditions of the assessment room does not mean that the person does not have difficulties (see above).

Some deaf people communicate through British Sign Language and will need a BSL interpreter.

Need to have eye contact and to see the speaker's lips but again absence of this in the ideal listening conditions of the assessment room does not mean that the person does not have difficulties.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home - e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Asking the deaf person if they can hear and understand them and if they would like any change to the seating arrangements. Asking the deaf person if they prefer the terms 'deaf', 'hearing impaired' or 'hearing loss'.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

The assessor should make sure they are face to face with the customer (not sideways on because this will not give full access to hearing or lip patterns). The assessor should not have the light behind them, as this may put their face in shadow. If they have to look down or away to type they should stop talking till they can look up again. They should not shout and should talk at a steady speed, checking frequently that the deaf person has understood what they are saying. They may need to give the deaf person time to process what they are saying.

If the customer has requested a BSL interpreter or lipspeaker, the assessment should not go ahead without this. Failure to provide an interpreter or lipspeaker if requested or needed is a breach of the Equality Act. The assessor should allow the interpreter or lipspeaker in consultation with the customer to decide on the best seating arrangement for the assessment.



Further reading:

Disability Matters is a free online e-learning resource for the UK workforce designed to challenge and positively change our own and others' fears, ideas and attitudes towards disability and disabled children and young people. Deaf Communication Matters uses short film clips of deaf children and young people sharing some of the typical barriers they encounter and show us simple steps to take and adjustments to make to overcome those barriers and enable successful interaction with them.

www.disabilitymatters.org.uk/course/view.php?id=72

[Understanding deafness](#)

www.ndcs.org.uk/family_support/childhood_deafness/understanding_childhood_deafness/

Dementia

Dementia

Overview of the health condition or disability



What is the condition usually called?

Dementia: There are over 100 different causes, but the most common types are listed below.



Are there any alternate names?

- Alzheimer's or Alzheimer's disease
- Vascular dementia or stroke-related dementia or Binswanger's disease
- Dementia with Lewy bodies (DLB)
- Parkinson's disease dementia
- Frontotemporal dementia (FTD) – sometimes called Pick's disease, frontal lobe dementia or Frontotemporal lobar degeneration
- Mixed dementia (usually Alzheimer's and vascular mixed)

NB Dementia is more common in over 65s but can develop in people in their 20s or 30s. The profile of dementia is different in those of working age, with less common forms such as FTD, DLB and alcohol related brain damage more frequent.



What is the generally preferred term when referring to someone with this condition?

'People affected by dementia' or 'people living with dementia' (though some people would prefer memory problems' - see later section on Communication approaches). Not 'sufferer'

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes

Typical for people to have good days when they are less impeded and bad days when they appear more disabled. Particularly true of dementias that affect younger people (i.e people of working age). Also characteristic of dementia with Lewy bodies, in which symptoms can fluctuate hour by hour.



What aspects of daily living can be worse and what might be constant?

Everyone with dementia is different and no two people will show the same symptoms. People struggle most with new things (learning a new phone or TV remote) and less with familiar things that they have learned a while back.

The loss of some skills may be exacerbated by psychological distress leading to an inability to carry out tasks that were previously possible. People can also be over-protective or risk averse and so leads to excess disability by helping too much. Likewise an unfamiliar environment or routine can cause confusion or distress.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

- May struggle with following a sequence because of loss of executive function. This means that many people will not be able to carry out a task (eg. preparing a simple meal) safely and reliably without support.
- May struggle with concentration, planning (eg. planning a route), organising (eg. managing money) or making decisions (eg. deciding between multiple choices).
- May struggle with short-term memory, hence with recalling events from earlier that day.
- May struggle with language and communication – problems following the thread of a conversation or finding the right word.
- May lose visuospatial perception, hence problems judging distances or objects (eg. stairs) in 3D.
- May struggle with orientation – not knowing the time or place they are in, even if somewhere familiar. Can make it easy to get lost or distressed.
- Prone to frustration or irritability, may be withdrawn, anxious, easily upset (mood swings) or depressed (tearful).
- May suffer hallucinations or delusions.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

- Dementia in people of working age is less likely to manifest as memory problems. Much more likely are problems with executive function (planning, sequencing and organising), concentration, visuospatial problems and behavioural changes (eg. apathy, poor judgement, loss of social conventions)
- People with working age dementia report 'autobiographical disruption' which means the plans that they had for the future life are now very different, leading to anxiety and depression and often changes in family dynamics



Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

- Anyone with dementia can lack insight into their condition or be in denial; this is more common in Alzheimer's than vascular dementia.
- It is unusual for a person with FTD to have insight into their behaviour and they may lack control over their behaviour but be unaware of it.
- If 'exposed' they may become distressed or angry and embarrassed. This can result in behaviours that others find challenging.
- A carer/family member/supporter may also be reluctant to discuss these things if the claimant can hear them and may be afraid to distress or anger them.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Dementia is a 'hidden' disability because the person looks normal. Over a short period they may speak and behave normally, although with time it may be apparent that they are struggling with certain things.

The person may also have problems with vision or hearing which exacerbates their dementia.



How is it best to ask about these areas?

Careful discussion about the challenges that they face without interrogating them but mindful that although the person presents well there may be many hidden issues.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

A report which includes assessment of 'activities of daily living' (using the phone, driving, managing money, cooking etc) is likely to be most informative, for example with the input of an occupational therapist or a report from a clinician (this maybe a neurologist, psychiatrist, psychologist or a member of community mental health team.)



Presenting symptoms

All the dementias listed above are progressive. How quickly, or slowly dementia progresses, varies greatly from person to person.

Symptoms of dementia are usually divided up into:

- Cognitive – poor memory, lack of executive function, problems with language and so on
- Mood – apathy, stress/depression, irritability, anxiety
- Perception – delusions, possibly hallucinations
- Behavioural – restlessness, agitation, sleep disturbance
- Physical – problems with coordination



Etiquette and common courtesies

- Sit at the same level as the person.
- Talk to them rather than asking someone else to answer for them
- Use the same language they do to refer to their condition
- Give them time and stop for a break if they need it

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Some people may be reluctant to discuss their diagnosis and may even prefer not to use the word 'dementia'. Alternative phrase may be 'memory problems'. They may (incorrectly) use 'Alzheimer's disease' to cover all forms of dementia.

It is very important to communicate appropriately.

- Stick to one point at a time using straightforward questions.
- Having too many choices can be overwhelming.
- Look for non-verbal cues.
- Make eye contact and smile.
- Try describing things in a different way (if not understood) using simpler words if necessary.
- May need support to express or understand verbal or written information. This problem may be exacerbated if they feel that they are under pressure.
- Allow extra thinking time.
- Letter or email contact may be preferred to refer to later.
- Phone contact may be acceptable, though some may need a supporter/carer available. (ideally plan the call in advance)

Depression

Depression



Overview of the health condition or disability



What is the condition usually called?

Depression



Are there any alternate names?

Clinical depression

Someone with depression may have a diagnosis of:

- Mild depression
- Moderate depression
- Severe depression
- Major depression or major depressive disorder

There are some other specific types of depression that you should be aware of:

- Seasonal affective disorder (SAD)
- Dysthymia, also called persistent depressive disorder or chronic depression
- Prenatal depression, also called antenatal depression
- Postnatal depression (PND)
- Post-adoption depression



What is the generally preferred term when referring to someone with this condition?

Someone experiencing depression/someone who has been diagnosed with depression

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

People with depression may be affected more or less severely on different days or at different times of day. Their ability to perform basic tasks, plan, make decisions and work may vary from day to day but they may either experience constant low mood, or often experience periods of feeling low. It is important to understand that people with depression may not feel low all the time and that feeling happy sometimes, enjoying some activities or sometimes feeling hopeful does not mean that the person does not have depression.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

Depression can affect all aspects of a person's life. Someone with depression may struggle with basic aspects of self-care such as getting out of bed, washing, dressing and eating. It can also affect their relationships with other people and their ability to participate in work or leisure activities. People with depression may be unable to concentrate, think clearly, plan, reason or make decisions due to low mood, lack of concentration, feelings of hopelessness or despair and/or suicidal feelings. Depression can also disrupt personal and/or work relationships due to low mood, irritability or problems concentrating or interacting with others.





They may also experience physical symptoms including disturbed sleep and an increase or decrease in appetite. People with depression can experience both mental and physical exhaustion making basic tasks very difficult to carry out. People with depression may be lethargic, or they may be agitated or restless.

Some common symptoms of depression include feeling down, upset, tearful, restless, agitated, irritable, guilty, worthless, empty or numb, isolated and unable to relate to others, finding no pleasure in life or in things they usually enjoy, feeling hopeless or despairing and feeling suicidal.

Someone with depression may avoid social events and activities they normally enjoy, lose interest in personal and romantic relationships, struggle to think or speak clearly, have difficulty remembering or concentrating on things, sleep more or less than usual, eat more or less than usual, lose or gain weight, move more slowly or feel restless or agitated, or experience physical aches or pains with no obvious physical cause.

They may also experience psychotic symptoms such as paranoia or hearing voices. While psychosis can be a symptom of other mental health problems, it can also be a symptom of depression. They may use self harming behaviours to cope with difficult feelings and may feel or act on suicidal feelings or urges.

Impacts on personal, social and physical functioning can make it very difficult to engage with health services. Someone with depression may struggle to leave the house and attend appointments due to a lack of mental and physical energy. This can affect their ability to access treatment. In some cases people can be embarrassed to talk about the extent of their worries or difficulties for fear of being judged or misunderstood.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Ask how the person's depression is affecting different aspects of their life including basic self-care, their ability to concentrate, plan and make decisions, their social life, work life and their personal relationships. Ask whether areas of basic self-care such as eating and sleeping have been affected and if they have difficulty concentrating. Ask if they have lost interest in things they used to enjoy.

Ask how they have been feeling.

Ask whether they feel low, worried or very sad a lot of the time, and what other sorts of feelings they have had.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Someone with depression may find it hard to admit that they are struggling to perform basic self-care tasks such as washing and dressing or may fear that they will not be believed if they have managed to perform these tasks on the day of the assessment. They may find it hard to mention the effects that depression can have on personal relationships. They may also find it hard to mention feelings they have had of wanting to take their own lives.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

The psychological and physical impact that depression can have on an individual can be extremely profound. People may find it difficult to understand and empathise with them, may tell them to 'cheer up' or 'think positive' and may fail to understand that someone with depression is not simply feeling sad,

is not lazy, is experiencing symptoms of a recognised medical condition rather than choosing to behave in a certain way and cannot simply decide to feel better. It is also important to understand that the mental and physical exhaustion and sense of defeat experienced by someone with depression can make it very difficult to perform or concentrate on simple tasks.



How is it best to ask about these areas?

Take their mental health problem seriously and be understanding and empathetic. Don't just focus on their physical ability to undertake daily activities, but ask how they are affected personally before, during and after.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

A letter from their GP can convey the impact of depression on the individual. They can confirm any physical symptoms such as disturbed sleep. They can also convey the extent to which depression impacts on the individual's daily functioning.



Presenting symptoms

It is very important to remember that someone with depression may not obviously look depressed. Depression is a mood disorder and is diagnosed according to how someone feels so it is best to focus on asking the person about their feelings and experiences rather than judging according to how they present. The health professional should not base their assessment on the person's physical presentation. It is important to be aware that people with depression may not have any visible signs or symptoms at all when presenting at a face-to-face assessment.

It is possible that the person may appear lethargic, restless, tired or fatigued, disinterested, tearful or irritable, but as the consultation is an abnormal situation the person may not display the symptoms that they usually experience.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

People with depression may struggle to motivate themselves to attend a consultation so it is important to provide as much advance notice as possible. They may have disturbed sleep and experience insomnia or excessive sleepiness so it can be helpful to schedule the appointment later in the day if possible. It can be useful to brief them on exactly what the consultation involves and what they will be asked to do. You could ask them if there are any adjustments that would make them feel more comfortable during the assessment e.g. ask if they would feel more comfortable if a friend or family member was to come with them or ask if they would prefer to do the assessment in their own home. Offer them breaks if they need it, provide water and tell them where the nearest toilets and exits are.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

A calm and patient approach. Do not assume the person lacks intelligence, or does not care, if they have difficulty responding to questions or appear as if they are taking no interest. Both reading and concentration may be difficult so comprehension may be slow. Keep questions straightforward and give people time to respond. Some antidepressant medication may also slow people down.

Some people with depression may appear irritable or angry as a result of their condition and it is easy to misinterpret this.

Include the person in the consultation process by asking them if there is anything that you can do to make them feel more comfortable. Let them know what to expect from the process. Ask them if they have any initial concerns about the consultation and see if you can address this.

Be understanding, empathetic, patient and try not to put the individual under any pressure. Encourage them to take their time. Be aware that the person may feel more worthless, low or upset as a result of answering the questions and let them know that they can have a break at any time. Also be prepared for what you would do if the person mentioned feeling suicidal or wanting to harm themselves.



Further reading:

[www.mind.org.uk/information-support/
types-of-mental-health-problems/depression/#.WDgtNX2gXpt](http://www.mind.org.uk/information-support/types-of-mental-health-problems/depression/#.WDgtNX2gXpt)

[www.mind.org.uk/information-support/
types-of-mental-health-problems/suicidal-feelings/#.WDgXkX2gXps](http://www.mind.org.uk/information-support/types-of-mental-health-problems/suicidal-feelings/#.WDgXkX2gXps)

Epilepsy

Epilepsy



Overview of the health condition or disability



What is the condition usually called?

Epilepsy



Are there any alternate names?

- Seizure disorder
- Grand mal
- Fits
- Petite Mal
- The epilepsies
- Epilepsy syndromes



What is the generally preferred term when referring to someone with this condition?

Person with epilepsy

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

Living with epilepsy and its unpredictable nature means individuals are constantly living with the possibility of having a seizure. This effects people's physical and emotional health.

Daily living can be made worse when a seizure occurs. It may take a long time to recover. It impacts on someone's physical and emotional health. After a seizure people can be confused, exhausted and have memory problems, sometimes for several hours or days. For some people with epilepsy they need to be looked after during and following a seizure. They may sustain an injury during a seizure and need to recover.

The ability to cook, personal hygiene and caring roles can all be affected. These needs might be constant, depending on the nature/ frequency of seizures, or they may only affect someone around the days they have a seizure. Side-effects from epilepsy medicines can compound these difficulties.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

Epilepsy is a complex and fluctuating condition that can affect individuals differently. It is a hidden condition and there is a lack of understanding across society about the impact epilepsy has on people. This increases the discrimination and barriers people face in education, employment and other areas of life.

Frequency of seizures is not a complete assessment of the impact epilepsy has on an individual's life. It is important not to focus just on the seizure itself, but the time before, during and after too, this can impact on all areas of their life.

Transport is an issue for people with epilepsy. Many people are unable to drive and will have limited access to public transport. Depending on frequency and type of seizures, some people may be unable to travel without support and will have difficulty getting about independently.

Seizures can be unpredictable and can happen anywhere, anytime. Some people will suffer from incontinence during a seizure.

Various triggers can cause people to have a seizure. For example, lack of sleep, hunger, thirst, irregular sleep patterns and stress should be avoided because they can cause seizures in people with severe epilepsy.

Seizures pose a risk to the individual and potentially those around them. As a result people with severe epilepsy require supervision when carrying out certain activities such as bathing, showering, cooking and travelling.





Seizures are not the only thing people have to contend with; for some people the recovery period following a seizure can take hours, or days and will vary for each person. The recovery itself will be different for each individual.

For example some people will need to sleep, while others may have periods of confusion.

Cognitive impairment and memory issues are common in people with epilepsy. This has an impact on daily life. People may be unable to retain information or concentrate for long periods, they may have poor memory and need support for example, with medication, to travel or to carry out everyday tasks such as cooking.

Epilepsy medication has significant side-effects for some people, effecting their memory or energy levels.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

- What happens to you when you have a seizure?
- Are your seizures controlled?
- How often do you have seizures?
- Do they happen at a particular time of day?
- Do they happen when you are awake, asleep, or both?
- Is there anything that makes your seizures more likely, such as lack of sleep, tiredness, stress, hormonal changes, flashing or flickering lights or patterns?
- Do you get a warning before a seizure?
- How long do your seizures last?
- How do you feel afterwards?
- How long does it take you to recover?
- Do you need any first aid/specific care during/following a seizure?
- What tablets do you take?
- Does your medication cause side-effects?
- Are you able to manage your treatments yourself?
- Have you ever had status-epilepticus (seizures lasting 30 minutes or more, or a cluster of seizures without complete recovery in-between)



Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Incontinence, memory and confusion, and possibly symptoms related to their epilepsy that could be, but not diagnosed as, mental health problems. Some people with epilepsy may downplay the impact it has while they try to remain strong and defiant in the face of their condition. They may also not see themselves as disabled.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

It is a hidden, fluctuating and complex condition, which affects people very differently. There is no control over when and where seizures will happen. There are a myriad of different types of seizures. It is rarely recognised that epilepsy is a life-threatening condition.

Not just seizures affect people's daily lives. Recovery periods must be taken into account as well as the side effects of medication. The unpredictable nature of the condition means people are at risk and need supervision and support with various activities.

"Trusting us and understanding that with uncontrolled epilepsy, it doesn't matter if you have had one seizure or have them every day. My daughter has to live her life as if she could have a seizure at any point. With no warning, life has to be run in a very different way."



How is it best to ask about these areas?

Assessors should listen to a person's description of their epilepsy and ask questions that relate to their condition. Questions need to delve deeper into the impact of seizures e.g. recovery periods, supervision requirements, types of seizures. They should not purely focus on frequency of seizures or physical examinations, (which are irrelevant for many people with epilepsy).

The assessor should discuss in detail any side effects of medication person may suffer as each person is different.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Difficult to be precise, but a statement from a healthcare professional who knows the client well is probably the most reliable, such as an epilepsy specialist nurse – but it is important to bear in mind that people do not usually visit a healthcare professional every time they have a seizure. Side-effects from medication can be as disabling as seizures, for some people with epilepsy.

Further reading:

- www.epilepsy.org.uk/info/employment
- www.epilepsy.org.uk/info/seizures-explained
- www.epilepsy.org.uk/info/memory/what-is-memory
- www.epilepsy.org.uk/info/stress
- www.epilepsy.org.uk/info/safety



Presenting symptoms

Unless someone has a seizure or is recovering from a seizure at the time of the assessment, there might not be any.

“I don’t need a wheelchair or crutches, but after a seizure (I have 10-15 a week), I cannot walk, or feed myself, usually for several hours.” This highlights the importance of discussing in depth what the claimant is like post seizure and not just how often they have a seizure.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Keep an open mind. Listen to what they say. Try not to jump to conclusions about how their epilepsy affects them. Don’t ask questions in different ways, unless the person clearly doesn’t understand the first time. Reflect their style of language. Allow time for understanding the questions and don’t move on unless you are sure the person has nothing else to say – They might need more time than usual, if the epilepsy or medicines cause cognition problems.

Fibromyalgia

Fibromyalgia



Overview of the health condition or disability

 *What is the condition usually called?*
Fibromyalgia

 *Are there any alternate names?*

- Fibrositis
- Muscular Rheumatism

 *What is the generally preferred term when referring to someone with this condition?*
Fibromyalgia

Commonly reported variability in functional restrictions

 *Do people with this particular health condition or disability find its impact on daily life can vary from time to time?*
Yes

 *What aspects of daily living can be worse and what might be constant?*
The impact of all of the above aspects of daily living can vary from time to time.



Common areas of daily life where functional restriction occurs

 *What areas of daily life will a person with this particular health condition or disability find challenging?*

All aspects of daily living may be affected, depending on the individual. These can include sleep, toilet, bath/shower, dressing, personal care, shopping, housework, laundry, gardening, preparing food, eating drinking) including employment, relationships, hobbies, socialising, writing, attending medical appointments, medication, medicinal therapies, coping with finances/bills/benefits. Also walking, standing, sitting or driving for any length of time.

 *Are there any areas that a Health Professional should ask about specifically to ensure a complete report?*

All of the above activities, but especially how sufferers cope with these activities repeatedly over the day and the after effects on their Fibromyalgia of carrying these activities out.

i.e. How often can they carry out the activity in a reasonable time, to a reasonable standard without worsening their condition?

Variability of their condition, are there any triggers such as hot/cold that makes things worse, do they have flare ups? If so how often and how long do they last for? Explore good days and bad days, what makes a good day and what makes a bad day. What can they do on a good day they would not be able to on a bad day, and what effect does that have on them?

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

The fatigue and pain of Fibromyalgia can affect memory and cognitive function (especially when under stress) therefore sufferers may need prompting about all aspects of their daily lives.

They may find it difficult to relate that they can do some of these activities, but not that it causes them pain/fatigue during & afterwards and/or they couldn't do it repeatedly.

The pain from Fibromyalgia can be excruciating & the fatigue profound at times, it's hard to get this across to an assessor when sufferers often look so well



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Pain, fatigue, cognitive function, depression, its unpredictability.



How is it best to ask about these areas?

Pain scale, medical reports, a diary of a bad day from sufferer, depression scale, report from primary carer/family member.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

GP, Occupational therapist, Rheumatologist, Rheumatology Nurse, Neurologist, Physiotherapist, Psychologist, Pain Specialist, Psychiatrist, Psychiatric Nurse.

Presenting symptoms



Pain, fatigue, poor concentration/memory, anxiety (stress).



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Ground floor consultation room with disabled access, disabled access toilets, comfortable chairs and explain to sufferer that they can get up/change position if they need to.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Normal conversation, but give time to think through answer.



Further reading:

www.fmauk.org

HIV

(Human Immunodeficiency Virus)

Overview of the health condition or disability



What is the condition usually called?

HIV (Human Immunodeficiency Virus)



Are there any alternate names?

- HIV/AIDS*
- AIDS* (Acquired Immune Deficiency Syndrome)
- HIV infection (some clinicians may use this terminology although it is unlikely to be used by individuals)

* NB: HIV and AIDS are not the same thing, though the terms are used interchangeably by some people and in some countries (e.g. USA). Some people living with HIV may be diagnosed with AIDS if they are diagnosed with one of a specific list of illnesses which are associated with a compromised immune system due to advanced HIV. Some people with HIV may provide evidence relating to a recent AIDS diagnosis, or diagnosis of an 'AIDS-defining illness'.



What is the generally preferred term when referring to someone with this condition?

Person living with HIV is the preferred term.

Please avoid:

- 'HIV sufferer/carrier'
- 'AIDS victim/patient'

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

A 2011 survey by NAT found the fluctuating symptoms most commonly reported by people living with HIV were:

- fatigue, exhaustion or lack of energy
- depression or anxiety
- gastro-intestinal problems (such as nausea, vomiting and diarrhoea)
- insomnia or difficulty sleeping
- neuropathy.

Some of these symptoms relate to the HIV infection; others are treatment side-effects – although it can be hard to disentangle the exact cause in some cases.

The cycle of fluctuation can be within a day, or over a longer period of time. For example, during a given day, someone may have problems with gastric and continence issues following the taking of medication in the morning, through to difficulty sleeping after taking medication at night. For others it can fluctuate over longer periods of time, so someone can feel well for a period before developing pain and fatigue, and then feeling well again several weeks later. It can be difficult to ascertain whether the fluctuation is caused by the HIV, HIV treatment or a combination of both. Changes to someone's HIV medication or interactions between HIV medication and treatment for other health problems can also have significant side effects.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

HIV is a complex condition which can affect any or all bodily systems. Despite the improvements in HIV treatment and condition management since the 1990s, some people still face substantial functional restrictions.

Due to the wide-ranging impacts of HIV, all aspects of daily life can be affected - so any of the physical activities and mental tasks relevant to the PIP assessment may apply, depending on the individual.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Given the potential complexity of HIV-related impairment, the health professional should ensure that the person living with HIV has the opportunity to provide information in relation to any or all descriptors.

People should be asked about the side effects of the medication. As the treatment is life saving, stopping treatment is not an option.

Some side effects are similar to HIV – chronic diarrhoea, nausea, fatigue, loss of concentration, insomnia, frequent nightmares and night sweats.



Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Assessors should be aware that many people living with HIV have experienced stigmatising reactions to their condition from others, in both personal and professional settings. This can include people working within health and care services. For this reason, someone living with HIV may be apprehensive about discussing their condition with a stranger, even a health professional.

Specifically in relation to symptoms, some people living with HIV may feel uncomfortable mentioning the following:

- the common problem of persistent severe diarrhoea and incontinence.
- their full mental health history, particularly relating to depression and suicidal ideation.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Someone's HIV infection may be currently well-managed with effective treatment, but this does not mean HIV has had no impact on their daily living and mobility. People who have been diagnosed late (after they should have started treatment), or many years ago (before modern treatments), have often experienced serious opportunistic infections and AIDS-defining illness which have life-long impact.

Some HIV-related illnesses are not common in the UK and so many non-specialist healthcare professionals may never have come across them.

A common misconception is that it is possible to see the impact of HIV; this often stems from ideas about the presentation of particular AIDS-defining illness and symptoms of advanced HIV, such as wasting or skin conditions. HIV is largely an unseen condition, and while someone people applying for PIP may have visible barriers around mobility, for example, it is inappropriate to draw evidence from how well or unwell someone appears.



How is it best to ask about these areas?

The most important thing is to ask the individual about the impact of HIV on their daily living and mobility, without making prior assumptions about how HIV-related symptoms should present.

It may be necessary to listen very carefully to the conditions described. For example, TB meningitis can be misheard as 'TB and meningitis'.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Evidence provided by an HIV clinician (consultant or specialist nurse), is likely to be most comprehensive. As HIV is a specialist area of medicine, GPs tend not to be as closely involved in managing treatment and care, although they may provide evidence on some functional impacts. GPs may not always be aware that an individual has a diagnosis of HIV.

Non-medical evidence provided by social workers, support workers and others who provide non-clinical support to people living with HIV will also be relevant to understanding impact on daily living and mobility.



Presenting symptoms

As stated above, not all symptoms which are associated with HIV will be visible or easily identified in a superficial examination.

However, some of the range of symptoms which may be apparent in a consultation are:

- Breathlessness due to repeated fungal pneumonia infections.
- HIV related neurocognitive impairment that can affect memory, concentration and co-ordination.
- Pain related to neuropathy (nerve pain) particularly in the hands and feet.
- Pain related to lipodystrophy (fat redistribution), especially on the pads of the feet when walking and buttocks when sitting.
- Osteopenia and osteoporosis.
- Frailty.
- Anxiety in social situations.
- Side-effects of medication including chronic diarrhoea, nausea, fatigue, loss of concentration, insomnia and sleep disturbance.

Etiquette and common courtesies



It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

The key courtesy to show someone living with HIV is to treat them with the same ease and respect as someone with any other condition.

There is no risk of HIV transmission during an assessment, so taking extra precautions or treating someone differently based on an unfounded fear of HIV transmission risk would be stigmatising, discriminatory and undermine trust during the consultation.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

The most important aspect of effective communication with someone living with HIV is to avoid using stigmatising language or displaying judgemental attitudes relating to HIV. Using preferred terminology (people living with HIV'), rather than inaccurate or loaded terms ('AIDS patient', 'victim' or 'carrier'), is one way of avoiding stigmatising behaviour.

A key example of stigmatising behaviour to avoid is asking someone living with HIV how they acquired their condition. This is an intrusive question which adds no value to the consultation.

A significant proportion of people living with HIV in the UK were born in sub-Saharan Africa and some came to the UK as refugees. It is worth keeping in mind that some will have experienced trauma, physical and sexual violence. Special care should be made to gather background information about this in a sensitive manner.



Further reading:

Basic facts, myths and FAQs about HIV:

www.nat.org.uk/we-inform/do-i-understand-hiv

www.nat.org.uk/we-inform/FAQs-%26-Myths

Free e-learning module on HIV for health and care workers:

www.nat.org.uk/we-inform/training-and-learning/e-learning

[NB - being updated, will be live in early 2017]

NAT report, Fluctuating Symptoms of HIV:

www.nat.org.uk/sites/default/files/publications/August-2011-Fluctuating-symptoms-of-HIV.pdf

NAM list of HIV-related illnesses:

www.aidsmap.com/HIV-related-illnesses/page/1254976/

Myalgic Encephalomyelitis (ME)

Myalgic Encephalomyelitis (ME)

Overview of the health condition or disability



What is the condition usually called?

Myalgic Encephalomyelitis (ME)



Are there any alternate names?

- Chronic Fatigue Syndrome (CFS)
- Post Viral Fatigue Syndrome (PVFS) this is a term that GPs may often use in the early stages of the illness



What is the generally preferred term when referring to someone with this condition?

Myalgic Encephalomyelitis (ME)

ME and CFS are classified by WHO as neurological conditions (ICD10 G93.3) and this classification is recognised by the Department of Health. ME and CFS were included in the National Service Framework for Long Term Neurological Conditions. ME and CFS have a clinical read code of F286, denoting them as diseases of the nervous system.

There are an estimated 250,000 people with ME or CFS, of which 25% are severely affected. ME and CFS affects people of all ages, including children and young people, all of whom can become severely, or very severely affected.

There is no known single cause of ME or CFS, although for many it may be a viral trigger, and for some the infection may persist. Some may have a sudden onset, where for others it may be a slow and gradual process, with no easily identifiable trigger. There is no known cure, treatment, or specific diagnostic test for ME or CFS. Diagnosis is made through taking a detailed history, exclusionary tests and use of diagnostic criteria ie ME International Consensus Criteria (2011) for ME, and Fukuda et al criteria (1994) for CFS.

NB - Do not drop 'Syndrome' from Chronic Fatigue Syndrome (CFS) and use the term Chronic Fatigue (CF) as claimants may feel offended and that the assessor does not really understand their condition – as CFS has a neurological classification with a set of physical symptoms which makes up a complex condition, whereas CF is classified as a somatoform disorder (mental health).

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

As with many long-term conditions, people with ME or CFS experience different levels of severity, from mild, moderate, severe and very severe, and for some it may be a fluctuating condition, whilst for others it can become a multi-system, multi-organ illness, with little respite from the multitude of symptoms, and requiring 24/7 care, and assistance with all their personal needs. As with other long term conditions, for which there is no cure, fluctuation of ME or CFS is usually between the different levels of severity, and all are prone to prolonged relapses. Prognosis is often poor, with those who have been severely affected for more than 5 years having about 2% prognosis of any appreciable improvement (CMO Report on ME/CFS 2002)

Windows of ability to do a task, even a small one, can often be brief, and the person will then suffer the impact of the physical and cognitive effort needed. Remember each person is an individual and will be affected in their own way by these conditions.

Due to fluctuation of the condition for the claimant, sometimes hour to hour, let alone day to day, it may prove difficult to ascertain the level of functionality of the claimant for more than 50% of the time, and what they are able to achieve safely, reliably, repeatedly and in a timely manner, therefore more expansive questions may be needed about ability/ functionality, along with talking to the carer, to ascertain overall impact on their daily activities and mobility.

Assessors need to remember that most people who live with a chronic long term condition often try to remain positive, and continue to think of what they can do, rather than what they can't do, even if a physical or cognitive activity will impact and exacerbate symptoms. This is particularly relevant to ME when, due to Post Exertional Neuroimmune Exhaustion (PENE), something which is achievable one day, may not be achievable again the next day, or even a week later, but because they are able to achieve something once, or occasionally, for their self-esteem, they may answer Yes if asked if they can do something. Therefore, follow up questions need to be asked, as to how often they manage to achieve this activity; what impact it has on them, and how long that impact can last for?





What aspects of daily living can be worse and what might be constant?

ME and CFS are potentially severe, disabling, complex and chronic long term neurological conditions which become, for many, multi-system and multi-organ. Symptoms can be overwhelming, and therefore all aspects of daily life are usually affected.

Pain, for most, is unrelenting and unremitting, with analgesics often seeming ineffective. It is often widespread and migratory including muscle and/or multi-joint pain, as well as abdominal pain, with most finding the pain in their head, or headaches of a new type, pattern and severity having a large impact on them.

People with ME or CFS experience sleep which is dysfunctional, and unrefreshing. Some may want to sleep much of the time, often in early stage of the illness, whilst others, although tired, find sleep almost impossible, even with medication, and also may have sleep reversal, or a chaotic sleep pattern. Vivid dreams and restless legs are also often reported. Along with other symptoms this impacts not only on their daily lives and their ability to cope, but also that of the carer, who has to see to their every need, including cooking a main meal if they are hungry in the middle of the night, toileting etc.

Many have gastro-intestinal problems, so nutrition can be challenging for all those living with ME or CFS due to lack of appetite, nausea, food sensitivities and/or intolerances.

The moderately affected will be restricted in their ability to prepare and cook a simple meal, and may not be able to achieve this for more than 50% of the time – they are likely to require assistance ie someone may help them cook a larger quantity of meal on one day which can then be reheated on other days. The severely/very severely affected will be unable to prepare or cook a simple meal and may have problems eating; finding eating too exhausting, suffer from nausea, some may choke, or lose the ability to swallow, and may be tube fed.

For all those with ME or CFS there is no cure for their condition, nor a therapy treatment suitable for all, however monitoring of their condition, 24/7, day and night, is vitally necessary, as is supervision. They are likely to need assistance with medication, not just reminders. They also need careful monitoring due to hypersensitivity and intolerance to medication and treatment, which can make managing, not only their ME or CFS, more complicated, but also any co-morbid condition. If they are able to tolerate

the medication/treatment, it is likely to be at a reduced level to the usual therapeutic dose/amount. This is particularly important for the severely/very severely affected who will require monitoring and supervision 24/7.

For washing and bathing the moderately affected will be restricted in their ability to bathe themselves, eg unable to wash lower extremities, and may require assistance or aids. They are also likely to have the reduced number of times they bathe to reduce impact, and due to lack of energy/feeling unwell. The severely/very severely affected will be unable to bathe themselves and will usually require assistance to wash their whole bodies, they will use aids, eg a seat, and will have severely reduced the number of times they bathe. Sitting will cause them to feel unwell, and the experience will be exhausting, and could take days to recover from. Even a gentle shower can cause great pain, as they often find even touch painful, they may also suffer sensitivities to products. Even to wash their hands/face or brush their teeth can be too much for some, and some find it difficult to control body temperature, so water temperature can affect them.

For toileting needs/incontinence the moderately affected may require assistance with these, including any incontinence and menstruation. For the severely/very severely affected they will be unable to see to their toilet needs independently, requiring help and support. Some may use a commode by the bed whilst others will try, with assistance, to make it to the toilet if close by, others may be catheterised or wear incontinence pads. Some people may, even with assistance be unable to make the toilet in time and will wet/soil themselves, and will need assistance changing clothes/bedlinen and cleaning up. Menstruating female will require extra help with changing pads, cleaning themselves, changing clothes/bedlinen etc.

For dressing/undressing the moderately affected may require some assistance or aids, or may have adapted clothes for ease eg velcro, slip on shoes, front fastening clothes. For the severely/very severely affected they will require assistance with all dressing and undressing, and some may be unable to achieve anything on their own. Clothes are often painful to wear so will adapt clothes. As they are usually bedbound, they will often wear nightclothes which are soft on their skin.

For communication, understanding, and engagement, it is important to keep questions as clear and concise as possible, giving the claimant time and understanding, especially as the impact of their symptoms increase as the assessment progresses, making it difficult for the claimant to comprehend questions and formulate an answer. The claimant is also likely to experience difficulty comprehending the review of the assessment and what has been filled in on screen. Need also to be aware that sounds

in the room, even the sound of the assessor typing may have an adverse impact on the claimant's ability to formulate and answer questions and communicate, and also bright lights/sunlight can cause pain and be uncomfortable.

For the moderately affected they may occasionally engage socially and may require assistance to communicate, understand and engage, this is likely to deteriorate as the activity goes on, and the impact of symptoms increase. For the severely/very severely affected, they will only occasionally engage socially beyond core family/friends and only for a short time – the effort can take days to recover from. They will require assistance to communicate, understand and engage, and will only be able to communicate for very short periods of time, having difficulty formulating sentences, forgetting what they are saying, or losing the power of speech. They will often rely on their loved one/carer to explain things to them, and answer on their behalf, and the impact of pain and physical/cognitive activity will make communication more difficult.

For budgeting, the moderately affected may require assistance to make complex budgeting decisions with follow-up actions. For the severely/very severely affected they are likely to find budgeting decisions difficult and are likely to rely on close family/friends to help with decisions and following up ie phone calls (having it on speaker phone so others can help, as they may not understand what is being said or remember conversation) or writing a letter for them to sign.

For planning and following a journey the moderately affected may require some assistance, taking into account their reduced mobility, rest periods and exacerbation of symptoms. For the severely/very severely affected, by definition, this group is predominantly house/bedbound, so they would only occasionally/rarely make a journey and would require a lot of assistance and planning, even on a familiar route – if able to achieve it at all. Much prior research would be needed to allow for rest periods, wheelchair accessibility etc. They will require a carer with them at all times on the journey to assist and care for them appropriately, and to monitor their condition, identifying when their body is becoming physically distressed by the effort and exacerbation of symptoms.

For ability to move around, the moderately affected, by definition, will have a reduction in their mobility, some claimants may be able to walk a short distance, others will not be able to do this without aids/assistance, whilst others may use a wheelchair at times. For the severely/very severely affected, by definition, they are bed/housebound and require the use of wheelchair for their mobility, and will be unable to move any distance more than a few steps without assistance – if even that. Many will have difficulty sitting up for any length of time, and may require extra support aids in their wheelchair eg back/head support. They will require physical support from a carer to get in/out of bed, wheelchair or car. Some become paralysed and are unable to move at all.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

All aspects of daily life may be affected for those living with ME and CFS, from needing help from their carers with personal needs, such as washing and toileting, monitoring their condition, and administering medication, to having to have their carers do shopping, prepare meals, washing, changing clothes, bedding etc, dealing with any visitors, letters, phone calls, health professionals, DWP etc,- mobility will be impaired for those who are moderately/severely affected, from being able to walk short distances, to those being bed/housebound and needing a wheelchair for any mobility. The impact of doing any physical and/or cognitive activity will mean that they will be unlikely to be able to repeat the task, and may be unable to do so for many days after. Their condition can easily change not only from day to day, but from hour to hour, meaning if they feel a little better, they could get up for a while and maybe do a small task, an hour later they may be feeling so ill that they will be back in bed again.

When communicating, the claimant will find it increasingly difficult to communicate as they become more physically and cognitively fatigued. A classic situation will be the claimant will be speaking, and half way through a sentence will suddenly go blank and not know what the next word is, let alone what they have just said, or what they were going to say, or what the subject matter was at all. Even with prompting, they usually cannot recall, and the carer then needs to complete what they were trying to say. The classic statement from anyone with ME in this situation is 'Sorry, ME brain'

Those who are moderately affected, and certainly all those severely affected may be unable to do any of the basic daily and personal tasks, safely, reliably, repeatedly and in a timely manner, and for more than 50% of the time, and the severely affected would need a wheelchair for any mobility needs



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Ask about all areas of daily life as each individual will experience different impacts in different areas.

Should always ask claimant if they can do the specific task safely, reliably, repeatedly and in a timely manner, and for more than 50% of the time,

Extra questions which could be asked to obtain a clearer picture are:

- Have you got a specialist in ME who helps to manage your condition?
- Do you have a helpful and supportive GP who helps to manage your condition?
- What help and/or support, and aids, do you require to do a task?
- What is the impact of doing a task?
- How long usually would it take you to recover?
- How often would you be able to do the task?



Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

There have been many misconceptions, over the years, in respect of Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) despite them both being classified as neurological conditions by WHO (ICD10:G93.3)

Many will have met HPs who do not understand neurological ME or CFS, and have faced prejudice in the past, (from all sort of assessments), with them not acknowledging or recognising how debilitating their condition is and how it impacts on all areas of their lives. This can make the experience of assessment extra stressful, and may make them extra cautious and hesitant to discuss how their ME or CFS affects and impacts on their daily life.

Most people with ME or CFS do not have specialist/medical care, or a supportive GP - this is not the fault of the person, who may have tried every avenue to seek help to manage their condition, or to get supportive medical evidence. It is important to not make assumptions, or be judgemental, use the right tone when communicating, and give reassurance that you are not there to assess what condition they have, but to make a fair assessment of the impact of their condition on their daily life, but, that in order to do that, the claimant needs to be detailed of how exactly they are affected, acknowledging that this may be difficult and personal for the claimant.

Those who have been ill with ME for many years/decades have adapted, as much as possible, to the level of their disability, and have therefore come to accept their level of disability as their norm, (although they would give anything to be well again) and/or they have become unaware of just how much support and assistance they receive from their carer(s), and if they were left alone to cope for part of a day, would then realise how little, if anything, they actually can do on their own.

To ascertain the reality of their situation requires sensitive questions by the assessor, by gently asking eg to discuss toileting – asking ‘if your carer was not there, how would you access the toilet?’ it may be the claimant would eventually admit that they would wet the bed, which would be hard for them to acknowledge, or they may fall etc. Personal care is a particularly sensitive area for anyone.

Washing/Bathing may be difficult to discuss as may have been drastically reduced, so that they may be many months between washing hair due to the

pain and exhaustion it causes, or that they may only be able to have a bath/shower once or twice a week, or even less if in an acute relapse. Understanding should be given rather than a claimant feeling judged, as they are not likely to like it themselves, but have to do what they can in order to physically have the energy, or level of pain, to get through each day.

In all aspects of daily life the claimant may not realise how much their carer is caring for them, and assisting them, therefore they may have an idealistic view of how much they can do, and how often ie washing, food, monitoring condition/assisting with medication, toileting, dressing, bathing, moving around, going on journeys – often the carer protects the claimant and allows them dignity, so it is vital that you listen to the carer who has accompanied the claimant as they are likely to fully comprehend the abilities of the claimant. No person likes to acknowledge just how little they can do and achieve – and a good carer allows them their dignity, and enables and supports the person to do what tasks they are able to.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

All areas of ME and CFS are not well understood. Therefore there is not one area in particular, it affects all areas – please refer to the previous two sections for more detail on how people with ME and CFS are impacted on for daily living.



How is it best to ask about these areas?

It is important to not make assumptions, or be judgemental, use the right tone when communicating, and give reassurance that you are not there to assess what condition they have, but to make a fair assessment of the impact of their condition on their daily life, but that in order to do that the claimant needs to be detailed of how exactly they are affected, acknowledging that this may be difficult and personal for the claimant.

Recognise that the claimant is ill. Take time to ask the questions clearly and succinctly and allow the claimant time to formulate an answer. Listen to the carer. Be sensitive of personal areas, recognising that the claimant themselves may not realise their limitations, or do not want to admit they are not able to do something ie toilet themselves and reiterate every time “are you able to achieve that task safely, reliably, repeatedly and in a timely manner and for more than 50% of the time”



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

There is currently, and historically, an overwhelming national inequality of care in the NHS for people with ME or CFS, with the majority having little or no specialist/medical care, and often not having a GP who understands the condition, feels sufficiently knowledgeable to manage the condition, or is supportive. This also results in difficulty for claimants to provide supportive medical evidence.

If the claimant is fortunate enough to have a specialist in neurological ME, and/or an understanding and supportive GP, managing their condition, then they would be able to provide medical evidence.

However, many with ME or CFS have become abandoned in the community with no, or little, care and support, and are dependent on family and/or close friends to be their primary carers – and the carer would therefore be the best person to convey the impact of their ME or CFS on their daily life. A person with ME or CFS therefore may be unable to provide medical evidence, despite exploring every avenue – they should not be penalised for the paucity of specialist care and lack of understanding HPs.

As there are no specific tests, blood tests may show some aberrations but no conclusions, so the only thing that could be presented is a supportive letter, which is really a confirmation of their condition, what management if any, is helpful unhelpful, and reiteration of their symptoms and how they impact on the claimant’s life.

Be aware that people with ME or CFS may have other co-morbid conditions which may have supportive evidence.



Presenting symptoms

ME and CFS are complex, chronic, disabling and individualistic neurological conditions, which are still very misunderstood by Health Professionals. There is no known cure, treatment, or specific diagnostic test for ME or CFS.

Many surveys of thousands of people with ME or CFS overwhelmingly show that a biomedical approach of symptom management, pacing, and on-going care by supportive and understanding HPs, is found to be most beneficial and helpful approach to living with, and managing, their ME or CFS.

Research has shown that people with ME or CFS experience dysfunction/dysregulation of the central and autonomic nervous systems, neuro-endocrine systems, including the Hypothalamic Pituitary Adrenal (HPA) axis, immune system, dysfunction of cellular energy metabolism and ion transport, cardio-vascular including orthostatic intolerance (OI) and postural orthostatic tachycardia syndrome (POTS), as well as genetic abnormalities.

On examination, assessors may find eg swollen lymph glands etc, but they are unlikely to find extensive physical manifestation of symptoms, but this does not mean that the symptoms are not there eg. muscle weakness without muscle wasting/deconditioning and joint pain without swelling etc. Researchers believe this could be due to an overactive immune system which attacks the body, without harming it, causing symptoms.

People with ME or CFS usually experience pain, throughout their body, which is often unrelenting and unremitting, along with overwhelming fatigue with any physical or cognitive activity, which becomes more profound with its characteristic delayed onset, and exacerbation of symptoms. This causes a profound impact on basic daily activities such as bathing themselves, preparing and/or eating a meal, mobility etc.

People with ME or CFS experience sleep which is dysfunctional, and unrefreshing. Some may want to sleep much of the time, often in early stage of the illness, whilst others, although tired, find sleep almost impossible, even with medication, and also may have sleep reversal. Vivid dreams and restless legs are also often reported. Along with other symptoms this impacts not only on their daily lives, but also on their ability to cope with an assessment.

They have impaired cognitive functions, resulting in impairment of concentration, calculation difficulties; memory disturbance; spatial disorientation; difficulty with word retrieval and processing information and categorizing.

A core symptom of ME and CFS, in addition to eg pain, and flu-like symptoms, is Post Exertional Neuroimmune Exhaustion (PENE). PENE follows either physical

or cognitive activity, and malaise, fatigue, pain and other symptoms are exacerbated and worsen. There is the characteristic delayed onset and a pathologically slow recovery period.

Normal fatigue, seen in healthy people, is proportional to the intensity and duration of activity, followed by a quick restoration of energy. For people with ME or CFS, PENE is characterized by a pathologically low threshold of physical or mental fatigability, exhorting pain, and an abnormal exacerbation of symptoms in response to exertion, followed by a prolonged recovery period.

The underlying pathophysiology of PENE involves a profound dysfunction of the regulatory control network within and between the nervous systems. This interacts with the immune and endocrine systems affecting virtually all body systems, cellular metabolism and ion transport. The dysfunctional activity/rest control system and loss of homeostasis result in impaired aerobic energy production and an inability to produce sufficient energy on demand.

The impact of PENE on the daily life of someone with ME or CFS, is an abnormally quick reaction to any activity or physical/mental exertion, leading to a prolonged adverse reaction on their symptoms. This post-exertional exhaustion and symptom flare can be immediate or delayed, and is not relieved by rest. There are measurable, objective, adverse responses to normal exertion, resulting in exhaustion, extreme weakness, exacerbation of symptoms, and a prolonged recovery period. Therefore a person may achieve a task or conversation etc for a shorter amount of time than normal, but will then, usually, be unable to repeat this task again later that day, the next day, or possibly in subsequent days.

All with ME will be affected by PENE/fatigue as a result of physical or cognitive activity, as well as multiple other symptoms which includes; pain (which can be unrelenting and unremitting), flu-like symptoms, dysfunction of central and autonomic nervous systems, cognitive dysfunction, headaches, muscle weakness (without deconditioning), cardio-vascular, immune and sleep dysfunction, and intolerances and sensitivities eg to medication, anaesthetics, light, sound, heat/cold.

For all those with ME or CFS there is no cure for their condition, nor a therapy/treatment suitable for all, however monitoring of their condition is vitally necessary, as is supervision. They are likely to need assistance with medication, not just reminders. They also need careful monitoring due to hypersensitivity and intolerance to medication/treatment, which can make managing not only their ME or CFS more complicated, but also any co-morbid condition. If they are able to tolerate the medication/treatment, it is likely to be at a reduced level



to the usual therapeutic dose/amount due to the intolerance/sensitivity. This is particularly important for the severely/very severely affected who will require monitoring and supervision 24/7.

As with all people with long term conditions, people with ME or CFS can have pre-existing, or develop co-morbid conditions, which can add extra complexities to the impact on their daily lives, and must be taken into consideration.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

People with ME or CFS may have rested for many days to enable them to do the assessment, whether they are able to attend a centre, or are having a home visit, and may experience an exacerbation of symptoms for many days/weeks following assessment. If they have travelled to a centre then they may need somewhere quiet and dark to lie down to rest, both before and after the assessment.

Obviously if in a Centre explaining where the disabled toilet is, and a rest area if available, and offering assistance generally is helpful. A warm and friendly welcome, and reassurance will hopefully make the experience less intimidating and more relaxed.

Be kind, reassuring, repeatedly stating that you are there to assess how their condition impacts on their daily lives, not the condition themselves. If the claimant states that they have experienced prejudice in the past/have not had a good experience with the DWP in the past, give extra reassurance.

If the person says that they have ME, use that term throughout the assessment and on your forms, if they state that they have CFS, again use that term throughout the assessment and on your forms. Never drop the “syndrome” from Chronic Fatigue Syndrome and use the term Chronic Fatigue as this may well cause offense, as CFS is a neurological condition with a set of physical symptoms which makes up a complex condition, whereas CF is a mental health condition, and the claimant will feel that the assessor has no understanding of their condition.

Use all the common courtesy and etiquettes that you would use for anyone with a chronic long term debilitating condition. Try and recognise, if possible when the claimant is deteriorating and becoming more physically and cognitively distressed – ask if they want to stop, take a break etc. A claimant is likely to want to continue, no matter how physically distressed they are getting, as they know if they stop then they will only get worse, and would then be unable to continue. They will know that it will already take a long time to recover from the assessment, and they will not want to go through it again – so they will push themselves beyond what they usually achieve, recognising that they will have a prolonged relapse due to it.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Speak clearly, and if necessary more slowly, in a kind, calm, reassuring manner, and make eye contact. Explain that you are there to assess how their daily lives are impacted by their condition, not the condition itself. Please give the claimant time and understanding, as the impact of their symptoms will increase as the assessment progresses, which will make it difficult for the claimant to sometimes comprehend the questions, and formulate an answer - which may not be coherent. The claimant is even likely to experience difficulty comprehending when the assessor is reviewing what they have filled in on the screen. Need to also be aware that the sound in the room, including that of the assessor typing, may have an adverse impact on the claimant's ability to formulate and answer questions and communicate.

People with ME or CFS have impaired neurocognitive function. They will experience difficulty with concentration, or in processing information, which will become more profound as the assessment progresses, as will their short-term memory. They will find it increasingly difficult to construct a sentence, find the word they need, or in mid-sentence completely forget what they were saying, were going to say, and the subject matter. Even on prompting what they were saying, they will probably have absolutely no recollection. A classic statement when this happens is people say 'sorry it's my ME brain'.

Do not make assumptions about someone's intellect or mood - and acknowledge the impact of pain, fatigue, lack of quality sleep, and living with a long term chronic condition, on their ability to comprehend the questions, formulate an answer, and communicate in general. It is important to keep questions as clear and concise as possible, and please give the claimant time and understanding, as the impact of their symptoms will increase as the assessment progresses, which will make it difficult for the claimant to sometimes comprehend the questions, and formulate an answer - which may not be coherent. The claimant is even likely to experience difficulty comprehending when the assessor is

reviewing what they have filled in on the screen, it may be they need to try and read it for themselves, if able, to properly take it in.

Carer - It is important to have the claimant's carer present (obviously if the claimant is agreeable), who will be able to explain the question to the claimant, as well as understanding or clarifying what the claimant is trying to say. The carer will also be able to elucidate on the reality of what the claimant can actually achieve, or not, and the impact of their condition, as with most people with a chronic long term condition, they often may not realise/accept how much support and help they actually receive, to even do the most basic tasks, and also, if it has become a gradual decline over the years, the new level of ability has become 'normal' for them.

Be aware that people with ME or CFS, especially the more severely affected, will have heightened sensitivities. They will have pain and even light touch can be very painful; they may well have sensitivity to light and so will need blinds/curtains drawn and artificial lights low; temperature dysregulation, some will find a room too hot, some too cold; have a heightened sensitivity to noise, so a soft low tone would be appreciated, and a quiet environment. Need to also be aware that the sound of the assessor typing may have an adverse impact on the claimant's ability to formulate and answer questions and communicate. They may find reading the question easier to take in and formulate an answer, however some find reading extremely difficult.

Claimants may find it particularly challenging to communicate over the phone, as it is difficult to take in information/questions, retain the meaning, formulate an answer then have the ability to communicate it. Many claimants will find it difficult to use a computer and complete forms online, if they have the financial means to have a computer, internet, or phone in the first place.

Due to misinformation given to many HPs/benefit assessors over the years about ME and CFS, patients have often experienced prejudice and assumptions about,

not only their condition, but themselves as people for having the condition. Because of these negative experiences, claimants, and their carers, who will often have been dealing with situations, may be concerned about how the claimant will be treated when being assessed for PIP. It is therefore important for assessors to dispel any concerns by reassuring the claimant that they recognise that they have a complex and debilitating neurological condition, and that they are not there to judge them as people, nor their condition, but to make a fair assessment of the impact their condition has on their daily lives.

Do not drop 'Syndrome' from Chronic Fatigue Syndrome (CFS) and use the term Chronic Fatigue (CF) as claimants will feel offended and that the assessor does not really understand their condition – as CFS has a neurological classification with a set of physical symptoms which makes up a complex condition, whereas CF is classified as a somatoform disorder (mental health).

Keep repeating, when following up on a claimant's abilities to achieve something, "are you able to do this safely, reliably, repeatedly and in a timely manner and for more than 50% of the time."



Further reading:

Myalgic Encephalomyelitis International Consensus Primer for Medical Practitioners (2012).

This invaluable document can be downloaded from :

www.hetalternatief.org/ICC%20primer%202012.pdf

which includes the International ME Consensus Criteria (2011): -

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/pdf>

Canadian Consensus Guidelines -

A Clinical Case Definition and Guidelines for Medical Practitioners (2003):

http://sacfs.asn.au/download/consensus_overview_me_cfs.pdf

BRAME Information and Symptoms of ME leaflet (2015)

Motor Neurone Disease

Motor Neurone Disease

Overview of the health condition or disability



What is the condition usually called?

Motor Neurone Disease



Are there any alternate names?

- Amyotrophic lateral sclerosis (ALS)

This is the most common form, with both upper and lower motor neurone involvement. This form of the disease is characterised by weakness and wasting in the limbs. Someone may notice they are tripping when walking or dropping things.

- Progressive bulbar palsy (PBP)

PBP affects about a quarter of people diagnosed, and involves both the upper and lower motor neurones. Symptoms may include slurring of speech or difficulty swallowing.

- Progressive muscular atrophy (PMA)

PMA affects only a small proportion of people, mainly causing damage to the lower motor neurones. Early symptoms may be noticed as weakness or clumsiness of the hand.

- Primary lateral sclerosis (PLS)

A rare form of MND involving the upper motor neurones only, causing mainly weakness in the lower limbs, although some people may experience clumsiness in the hands or speech problems. As symptoms develop, some cases may be re-diagnosed as ALS.



What is the generally preferred term when referring to someone with this condition?

A person with MND

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes

MND is a rapidly progressing condition and is always fatal. In many cases people will lose all ability to move independently before they die. Additionally they are likely to lose the ability to speak and swallow food or drink. Commonly people with MND receive, fluid, nutrition and medication through gastrostomy or nasogastric tube. Advice is often given to undergo gastrostomy surgery while respiratory function is still strong enough, even if tube feeding is not yet needed as it will almost certainly be necessary as the disease progresses.

Respiratory muscle weakness occurs eventually in everyone with MND and ventilatory failure is the most common cause of death. Most commonly, respiratory symptoms occur as the condition progresses. However, very occasionally, acute respiratory problems are the presenting feature of MND with a diagnosis made after an acute admission to hospital.

Reduced respiratory function can cause symptoms such as breathlessness, orthopnoea, recurrent chest infections, disturbed sleep, nightmares, daytime sleepiness, poor concentration and memory, confusion, hallucinations, morning headaches and fatigue.

Non-invasive ventilation (NIV) is a method of providing ventilator support to a person with MND using a close-fitting mask that may cover the nose and/or mouth. The ventilator detects when the person tries to take a breath and delivers an extra flow of air to increase the volume inhaled.

Many people with MND will experience problems with saliva control. The salivary glands produce two different types of secretions: thin, watery saliva and thick mucus. Phlegm is a thick mucus secreted by the membranes of the respiratory passages. Someone with MND may experience thin, runny saliva that drools out of the mouth, thick tenacious saliva or phlegm. Thick

saliva and phlegm can be difficult to clear. People with MND may find they experience pooling of large amounts of thin watery saliva, which can cause drooling. In most cases, saliva problems are the result of poor saliva control, caused by poor lip seal and/or dysphagia. People who have MND may have weak muscles around the mouth, tongue and throat. This can make it more difficult to manage saliva, both in the mouth and during swallowing.

Others complain more of thickened mucus in the mouth and throat, which is difficult to swallow, or phlegm in the airways, which is difficult to cough up due to weakened respiratory muscles and an ineffective cough. Thick mucus can build up in the mouth and at the back of the throat of someone with MND due to dehydration, mouth breathing or open mouth posture, which can lead to evaporation of saliva. This may produce stringy mucus and cause airways to become blocked leading to choking. This can be very distressing for the person with MND and those who care for them.

An oral suction unit may be used to help with saliva and secretion management.

The MND Association “Just in Case” kit is a small box designed to hold medication that may be needed if a person with MND experiences a sudden change with symptoms such as breathlessness, coughing or choking.

Difficulty in coughing is often experienced due to weakness in inspiratory, expiratory and bulbar muscles. Cough augmentation techniques may be offered to people with MND who cannot cough effectively. These techniques can enable expectoration of phlegm or mucus from the throat or lungs, thus reducing the likelihood of A&E admission and emergency intubation.

A mechanical insufflation-exsufflation (MI:E) device is often used to support and enhance the ability of weakened inspiratory and expiratory muscles in order to improve the cough and aid secretion clearance and can help to prevent respiratory infections. Repeated aspiration and poor lung function can make people with MND vulnerable to chest infections and pneumonia.

80% of people with MND experience slurred, quiet or complete loss of speech because of spasticity and weakness of the tongue, lips, facial muscles, pharynx and larynx.

This dysarthria can have a significant impact on emotional wellbeing because it can cause isolation, loss of intimacy, loss of identity, frustration, fear and anxiety, low self-esteem, a loss of control and increased sadness and depression.

Augmentative and alternative communication (AAC) is an important clinical intervention for many people MND. The term AAC covers a wide range of techniques and communication aids that support or replace spoken and/or written communication. These may be used to communicate face-to-face or electronically. AAC is commonly used to refer to electronic communication aids and products (high-tech) but equally it includes simple, non-electronic (low-tech) options such as pen and paper, gesture, signing, symbols, communication charts, and letter, word or picture boards or books. High-tech examples include voice output communication aids (VOCAs) apps, and specialist soft and hardware including devices operated by eye movement as this is the only function that is never lost.



What aspects of daily living can be worse and what might be constant?

MND is rapidly progressive – symptoms will inevitably become more debilitating, It is not possible to predict the order in which symptoms will become manifest or their severity.

In addition to physical changes MND also includes non-motor symptoms, one of the most common being cognitive change. Research has shown that changes can occur in the frontal and temporal areas of the brain, which affect thinking, reasoning and behaviour.

For many people the changes will be subtle and have little or no effect on daily life, but a small number of people will develop frontotemporal dementia and need additional support.

People with MND appear to fall into four groups:

- 50% are unaffected by cognitive change
- 35% experience mild cognitive change, with specific deficits in executive functions, language and/or social cognition
- 15% develop frontotemporal dementia (FTD), either at the same time or after diagnosis of MND
- 15% of people diagnosed with FTD go on to develop MND

Changes can affect:

Executive functioning - this may lead to problems with:

Setting and achieving goals

Planning and problem solving

Responding to new situations

Shifting attention or dividing attention between different tasks

Initiating and inhibiting responses.

Language - some people also show changes in their ability to understand and produce spoken or written language.

Behaviour - behavioural impairment is a recognised feature of MND and problems may include socially inappropriate behaviour, disinhibited comments, impulsivity, apathy and inertia, loss of sympathy and empathy for others, and perseverative, rigid, stereotyped or compulsive behaviour.

Social cognition - understanding and interpreting thoughts/beliefs/feelings of other people.

A small but significant minority of people experience severe changes that will be diagnosed as frontotemporal dementia (FTD). These changes are most often in behaviour and executive skills, but sometimes they are in language or conceptual understanding.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

An MND diagnosis is always a diagnosis of a terminal condition.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

This is a summary of the common symptoms and effects of MND:

- Pain and discomfort; are not caused directly by MND, but may have several indirect causes
- Muscle cramps and spasms; may be relieved by changing position when resting in a chair or bed
- Stiff joints; can be helped with gentle exercise
- Incontinence; is not usually associated with MND, but may occur if mobility is restricted and getting to the toilet becomes more difficult
- Bowel problems; are not usually caused directly by MND, but constipation may occur due to restricted mobility and/or changes to diet - diarrhoea can sometimes happen with a severely constipated bowel
- Speech and communication issues; occur for most people living with MND
- Eating and drinking difficulties: may become an issue if swallowing is affected and tube feeding will be considered
- Saliva and mucous: may cause issues if problems occur with swallowing - saliva may pool in the mouth or it may become thick and sticky
- Coughing and a feeling of choking; may occur as a result of food or saliva becoming lodged in the airway
- Breathing; respiratory muscle weakness affects most people with MND
- Cognitive changes; may occur for some people living with MND, where difficulties with memory, learning, language and poor concentration may be experienced - this is commonly known as cognitive change

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

An MND diagnosis is always terminal, with all treatment being palliative.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Paralysis, potential cognitive impact and loss of speech.



How is it best to ask about these areas?

Be sensitive and empathetic, Probe how they are completing tasks and well as why they cannot



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Medical report from GP, specialist nurse or consultant confirming diagnosis. DS1500 confirming terminal stage of the condition



Presenting symptoms

Please see earlier information.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

- Sensitivity when discussing the terminal diagnosis
- Recognition that cognitive changes may be present

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

This would have to be considered on a case-by-case basis.



Summary:

- Motor neurone disease (MND) is a fatal, rapidly progressing disease that attacks the motor neurones, or nerves, in the brain and spinal cord; messages stop reaching the muscles
- It can leave people locked in a failing body, unable to move, swallow, eat or drink, talk and eventually breathe
- It kills a third of people within a year and more than half within two years of diagnosis
- It kills six people per day in the UK, this is just under 2,200 per year
- There is no cure
- There is no single diagnostic test for MND; diagnosis is based on features in the clinical history and examination, usually accompanied by electrophysiological tests, blood tests, lumbar puncture and muscle biopsy
- The purpose of these tests is to exclude other neurological conditions; In the early stages of MND, symptoms can be similar to other conditions, meaning people may spend months seeing various specialists and undergoing unsuccessful treatments until MND is confirmed
- MND attacks the nerves that control movement so muscles no longer work but does not usually affect the senses such as sight, sound and feeling
- Riluzole is the only licensed drug available that may help in MND and trials have shown it can extend survival by around three to six months if taken for 18 months; its benefit does not show improved muscle strength
- It affects people from all communities and onset can be at any age during adulthood
- Around 35% of people with MND experience mild cognitive change, which can cause issues in executive functions such as planning, decision-making and language
- A further 15% of people with MND show signs of frontotemporal dementia which results in more pronounced behavioral change.
- Six people per day are diagnosed with MND in the UK
- MND affects up to 5,000 adults in the UK at any one time

Multiple System Atrophy

Multiple System Atrophy



Overview of the health condition or disability



What is the condition usually called?

Multiple System Atrophy



Are there any alternate names?

- Atypical Parkinsonism
- Shy Drager
- Parkinson's plus
- Parkinsonism



What is the generally preferred term when referring to someone with this condition?

Multiple System Atrophy or MSA

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes

The symptoms vary considerably from day to day, week to week, and time of day. When blood pressure drops, which is a common problem, all symptoms are suddenly worsened. Urine infections and chest infections are frequent problems, which also make symptoms suddenly worse, and although treatment with antibiotics may improve things they are not likely to completely regain their pre-infection function.



What aspects of daily living can be worse and what might be constant?

The condition is progressive so there are no real constants, all symptoms get progressively worse. Over time people become less and less able to manage activities of daily living for themselves and so require more assistance with washing and dressing, food preparation, feeding, communication, toileting, socialising and movement.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

All areas of daily life.

MSA is a progressive neurological condition that causes nerve cells to shrink in three areas of the brain. This leads to problems with movement, speech, swallowing, balance and autonomic functions such as bladder and blood pressure control. There is no cure and it leads to premature death (average lifespan from start of symptoms to death 5-7 years). In some circumstances, assessment will therefore be appropriate under the Special Rules.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Continence and bowel management. Mobility and history of falls/blackouts. Nutrition, especially use of thickeners or PEG. Ability to communicate. Cognitive and behavioural changes – need also to ask carers and professionals about this.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

- Continence issues – retention, urgency, frequency, nocturia
- Sexual/relationship issues – erectile dysfunction, speech and communication get progressively more difficult
- Mobility
- Personal hygiene issues and dressing/undressing
- Cognitive slowing
- Behavioural changes (the person with MSA is usually unaware of this)
- Psychological impact of a life limiting condition
- Palliative care - advanced care planning and end of life care



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

- Cognitive and behavioural changes
- Psychological issues
- Sexual/relationship issues
- Sleep problems
- Fatigue
- Emotional lability
- Depression



How is it best to ask about these areas?

Sensitively.

The person with MSA is likely to say all is well, as they have little insight into their condition, so it is vital that their spouse or carer is present if possible.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

- Neuro/Psychology report, cognitive report, psychiatry report, OT report
- Care log detailing all care given
- Clinic letters from Neurologist
- Telephone call to Parkinson's Nurse or MSA Trust Nurse Specialist.

Presenting symptoms



Difficulties with speech, slower response, quiet voice, difficulty expressing needs, emotional lability.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Invite them to bring carer or family with them

Breaks when they are fatigued, or may need a couple of visits

Toilet breaks and regular hydration

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Communication becomes very effortful, as whilst the person may well be able to understand the conversation it may be very difficult for them to input their point as they may well have cognitive slowing and difficulties forming their response. They will also fatigue quickly. They may well not describe the full extent of their care and needs as this is facing up to how much their condition has progressed, and it is hard to verbalise that deterioration. It may be appropriate to ask their carer to speak for them and then get their agreement that this is accurate. For some people communication is eased by using specialist communication aids.



Further reading:

Multiple System Atrophy, Wenning G., Fanciulli A. -Springer 2014
ISBN 978-3-7091-0686-0
www.msatrust.org.uk/

Multiple Sclerosis (MS)

Multiple Sclerosis



Overview of the health condition or disability



What is the condition usually called?

Multiple Sclerosis, MS



What is the generally preferred term when referring to someone with this condition?

Person with MS

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes

MS symptoms can vary enormously from one day to the next – even from one hour to the next. They might last for a few hours, or for days, weeks or months. Some people find certain triggers – such as heat*, stress, exertion or tiredness – make their symptoms worse, or make old symptoms reappear. *Heat refers to a change in a person's core body temperature. A rise could be due to the heat of the day, hormone changes or the person fighting off an infection or virus.



What aspects of daily living can be worse and what might be constant?

Many of the symptoms of MS can vary over time. Many people with the relapsing form of MS experience relapses, which can come on very suddenly, with no warning. They can last anything from 24 hours to weeks or even months. In some cases, people may recover almost completely between relapses, particularly in the early stages of MS, but in other cases they may be left with residual symptoms. However, every relapse does leave lasting damage to the brain and spinal cord which can accumulate. In most cases, some level of functional restriction is likely to be constant.

Other people with progressive forms of MS will have constant levels of disability or impairment which can worsen over time.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

MS affects everyone differently. No two people will have the same symptoms, and it's impossible to predict how someone will be affected. The only way to know how someone is affected is to ask them. It can affect many areas of daily life and impact how people move, think, see and feel. Physical symptoms of MS might commonly include vision problems, balance problems and dizziness, fatigue, bladder problems and stiffness and/or spasms.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

All areas of daily life should be explored to capture the impact of MS. It is essential that less visible symptoms and their impacts on daily life are explored, particularly fatigue, pain and cognitive difficulties. Fatigue – an overwhelming sense of tiredness with no obvious cause – is one of the most common symptoms of MS. For many people, but not for everyone, it is the symptom that affects them most, and can stop them from carrying out even basic actions. Even if a specific basic action is possible on a particular day, there may be varying consequences for that person physically or mentally. Asking about this will be very revealing in terms of how an individual can be affected day-to-day.

A health professional should ask about what tasks they are unable to complete on their own. The involvement of a carer or personal assistant usually implies they are unable to complete several daily tasks on their own.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Bladder and bowel problems are common in people with MS, but many people don't feel comfortable talking about them. Some people may be reluctant to leave their house for fear of having a bladder or bowel accident.

Depression and anxiety are 50 % more common amongst people with MS than the general population. Someone with low mood, anxiety or other negative effects on their psychological wellbeing may be reluctant to talk about it.

Cognitive issues including memory loss or difficulty explaining simple things. People with MS may be embarrassed to discuss this or may have difficulties recalling that they are affected in this way.

In a general sense, and as mentioned previously, people may not mention how completing any specific task, such as walking a certain distance, has an effect on their ability to function effectively for the rest of the day or even the day following. In a practical sense it may mean having to make a choice as to what activities are the most essential to be involved in during any particular day.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

MS can have a number of hidden symptoms with the least well understood being symptoms that cannot be seen. These include pain, fatigue and cognitive difficulties. These can be hard to identify and anecdotally, are often missed at the assessment.

The complex variability of MS symptoms must also be properly explored. People with MS have good days and bad days. How they are on any given day is not how they are going to be all the time.

For example, someone with cognitive difficulties may be able to explain an action but be unable to carry it out when asked.



The unpredictability of the condition can have an effect on day-to-day functioning. Appointments or itineraries may have to be changed at short notice, because of a fluctuation of symptoms.

People who come into contact with someone with MS, may not be aware the person has MS, because the person may only choose to make contact on a day when they feel able to function effectively.



How is it best to ask about these areas?

Ask about the pain and fatigue experienced whilst carrying out activities and the impact on daily life. How often do they experience this?

Ask them to describe what the people around them notice about their symptoms. Also, if they can remember what symptoms their medical team have discussed with them



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

All medical evidence provided by the claimant should be considered. The experience and insight of the person with MS into their symptoms is very important.

Evidence from a medical professional could include

a) Details about the symptoms of MS, for example changes to the person that are caused by damage to the brain and the spine

b) Associated mental health issues that arise from the effects of MS and having a long-term chronic condition. As the symptoms are many and varied, considering how the symptoms could inhibit or disable the person with MS is important. The list below includes some of the symptoms of MS, it is not exhaustive:

- fatigue
- vision problems,
- balance problems
- dizziness
- fatigue



- bladder problems
- bowel problems
- stiffness and/or spasms
- tremor
- swallowing
- speech
- cognitive problems (problems with thinking and communicating)



Evidence from specialist medical professionals, such as neurologists, may not always be available.

Typically clinicians will measure disability in multiple sclerosis using the Expanded Disability Status Scale (EDSS). This scale ranges from 0 to 10 in 0.5 unit increments and is based on an examination by a neurologist.

EDSS steps 1.0 to 4.5 refer to people with MS who are able to walk without any aid and is based on measures of impairment in eight functional systems (FS):

1. pyramidal - weakness or difficulty moving limbs
2. cerebellar - ataxia, loss of coordination or tremor
3. brainstem - problems with speech, swallowing and nystagmus
4. sensory - numbness or loss of sensations
5. bowel and bladder function
6. visual function
7. cerebral (or mental) functions
8. other

Each functional system is scored on a scale of 0 (no disability) to 5 or 6 (more severe disability).

EDSS steps 5.0 to 9.5 are defined by the impairment to walking.



- 1.0 No disability, minimal signs in one FS
- 1.5 No disability, minimal signs in more than one FS
- 2.0 Minimal disability in one FS
- 2.5 Mild disability in one FS or minimal disability in two FS
- 3.0 Moderate disability in one FS, or mild disability in three or four FS. No impairment to walking
- 3.5 Moderate disability in one FS and more than minimal disability in several others. No impairment to walking
- 4.0 Significant disability but self-sufficient and up and about some 12 hours a day. Able to walk without aid or rest for 500m
- 4.5 Significant disability but up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance. Able to walk without aid or rest for 300m
- 5.0 Disability severe enough to impair full daily activities and ability to work a full day without special provisions. Able to walk without aid or rest for 200m
- 5.5 Disability severe enough to preclude full daily activities. Able to walk without aid or rest for 100m
- 6.0 Requires a walking aid - cane, crutch, etc - to walk about 100m with or without resting
- 6.5 Requires two walking aids - pair of canes, crutches, etc - to walk about 20m without resting
- 7.0 Unable to walk beyond approximately 5m even with aid. Essentially restricted to wheelchair; though wheels self in standard wheelchair and transfers alone. Up and about in wheelchair some 12 hours a day
- 7.5 Unable to take more than a few steps. Restricted to wheelchair and may need aid in transferring. Can wheel self but can not carry on in standard wheelchair for a full day and may require a motorised wheelchair



- 8.0 Essentially restricted to bed or chair or pushed in wheelchair. May be out of bed itself much of the day. Retains many self-care functions. Generally has effective use of arms
- 8.5 Essentially restricted to bed much of day. Has some effective use of arms retains some self care functions
- 9.0 Confined to bed. Can still communicate and eat
- 9.5 Confined to bed and totally dependent. Unable to communicate effectively or eat/swallow
- 10.0 Death due to MS



Presenting symptoms

As mentioned above, the symptoms of MS are different for every individual and are very unpredictable. How someone with MS presents on the day of the assessment may not reflect their symptoms the rest of the time. Common symptoms of MS can include problems with balance and mobility, dizziness and fatigue. Some people with MS may have speech difficulties.

As anxiety and depression are more common in people with MS, their anxiety levels could be high.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

- On arrival, advise on location of basic facilities including accessible toilet and rest areas
- Ensure any companion is made to feel welcome and allowed to contribute to the assessment.
- Make eye contact and speak to both person with MS and companion even if the companion is providing most of the information.
- If someone appears to be in discomfort while waiting ask if any assistance can be provided.
- Be proactive in offering a break in the session. They may feel uncomfortable about asking for this.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Some people with MS may have cognitive difficulties, which may mean they find it difficult to take in and process information. They may need longer than other people to respond to questions. Some people with MS may have speech difficulties which make it harder for them to speak clearly.

Communication tips:

- Give the person time and wait for their response. Some people with MS find it difficult to think properly when they're put on the spot – so try to put them at ease, and don't pressure them to answer immediately

- Make your questions as clear as possible, and be prepared to repeat a question if necessary. Also consider asking the question in a different way.
- Don't assume that because someone has speech difficulties that they have cognitive difficulties
- If you haven't understood something, say so. If necessary, repeat it back to them to make sure you've understand
- Remember that speaking can be tiring for someone with MS, particularly if they have speech difficulties
- If someone has a carer or supporter with them, ask them for clarification on anything you don't understand or the person with MS is unable to explain

Further reading:

MS Society 'What is MS?'
<https://www.mssociety.org.uk/what-is-ms/>

National Institute for Health and Care Excellence (NICE):
Clinical guideline [CG186]: Multiple sclerosis in adults: management
www.nice.org.uk/guidance/cg186/chapter/Introduction

MS Trust 'Types of MS':
www.mstrust.org.uk/a-z/types-ms

MS Society: Information resources list
www.mssociety.org.uk/ms-resources/publications-list



Obsessive Compulsive Disorder (OCD)

Obsessive Compulsive Disorder

Overview of the health condition or disability



What is the condition usually called?

OCD Obsessive Compulsive Disorder

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

The presentation of the condition will be expected to vary over time but this would not be in the short term i.e little variability over hours but may vary over longer time periods. As an anxiety disorder the condition is reactive to stress, times of high anxiety can increase symptoms.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

The areas of life which are impacted will depend on the specific obsessions and compulsions experienced by the claimant. No two people would be expected to find this condition challenging for the same reasons.

Disrupting day to day life:

Repeating compulsions can take up a lot of time, and you might avoid certain situations that trigger the obsessions of the OCD. This can mean that you're not able to go to work, see family and friends, eat out or even go outside.

Obsessive thoughts can make it hard to concentrate and can leave you feeling exhausted.

Impact on your relationships:

You may feel that you have to hide your OCD from people close to you - or your doubts and anxieties about the relationship may make it too difficult to continue it.

Feeling ashamed or lonely:

You may feel ashamed of your obsessive thoughts, or as if they are a permanent part of you and can't be treated. You might feel that you can't talk about this part of yourself with others. This can make you feel very isolated. If you find it hard to be around people or go outside, then you may feel lonely.

Impact on your physical health:

Anxiety caused by obsessions can affect your physical health. Excess washing can lead to skin conditions for example



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Although everyone is affected differently a key area that the HP must address is reliability, specifically timeliness. Unless there is a co-morbid physical or cognitive condition the person will be able to both understand and physically complete activities but due to the compulsions they need to complete as a consequence of the obsession the activity may take much more than twice as long and the person does not have the option to just stop.



Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

The nature of the obsessions that are experienced can be upsetting for people to talk about. Examples of obsessions are the recurrent thought that you are going to push someone under a car, stab them or that you may do something violent or abusive. The thoughts may be blasphemous or sexually aggressive or inappropriate. It should be noted that obsessions are not a reflection of your personality; people with OCD are very unlikely to act on their thoughts because they find them so distressing and repugnant. There are no recorded cases of a person with OCD carrying out their obsession (Mind 2016: Understanding Obsessive Compulsive Disorder)



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Lots of people have misconceptions about OCD. Some people think it just means you wash your hands a lot or you like things to be tidy. They might even make jokes about it. This can be frustrating and upsetting, especially if people who think this are friends or family, colleagues or even healthcare professionals.



How is it best to ask about these areas?

It is important that the HP realises that the person living with OCD will most likely have full insight into their condition. They will be fully aware that their obsessions and compulsions but they will not be able to control them. As such the HP can discuss the difficulties the condition causes in an open and frank manner and will get a very clear and accurate description of the issues caused from the claimant



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Initially a GP would be expected to refer into secondary MH services for a diagnosis by a Psychiatrist. There are medications which are registered to treat OCD but these would usually be used in conjunction with therapy or to help manage symptoms whilst waiting for therapy. Antidepressants are recommended by NICE for treatment of OCD, medications such as diazepam (tranquilisers) can be given to help with the short term management of severe anxiety and beta-blockers (such as propranolol) may also be used to help manage the physical symptoms of anxiety such as palpitations, excessive sweating or tremor.

The therapy used is usually CBT and this can be carried out in Primary, Secondary or Tertiary Care depending of the severity of the condition. Primary Psychological therapy is often delivered via telephone or computer or sometimes 1-1 with a Psychological well-being practitioner; it typically lasts 4-12 weeks. Secondary care input would be more likely to be delivered by a specially trained Mental Health Nurse or Psychologist and would be over a longer duration. A person with very severe OCD may be referred to a specialist OCD service (Tertiary Care) but these are not available in all areas.



Presenting symptoms

Obsessions:

Obsessions are persistent thoughts, pictures, urges or doubts that appear in your mind again and again. They interrupt your thoughts against your control and can be really frightening, graphic and disturbing. They may make you feel anxious, disgusted or 'mentally uncomfortable'. You might feel you can't share them with others or that there is something wrong with you that you have to hide. You do not choose to have obsessions - but you might feel upset that you are 'capable' of having such thoughts.

Compulsions:

Compulsions are repetitive activities that you feel you have to do. The aim of a compulsion is to try and deal with the distress caused by obsessive thoughts. You might have to continue doing the compulsion until the anxiety goes away and things feel right again. You might know that it doesn't make sense to carry out a compulsion - but it can still feel too scary not to. Repeating compulsions is often very time consuming and the relief they give you doesn't usually last very long.

Compulsions can

- be physical actions (rituals such as washing or touching)
- be mental rituals (people who only have mental compulsions sometimes refer to their OCD as Pure O and may be activities such as checking the environment or yourself)
- involve a number (for example, you might feel you have to complete a compulsion a specific number of times without interruption such as counting or repeating a word)

Avoidance:

As insight is good you might find that some activities, objects or experiences make your obsessions or compulsions worse. For example, if you are worried that you might stab someone then you might avoid the kitchen because you know there are knives there. Sometimes it might feel easier to avoid situations that mean you have to do a compulsion. For example, if you have to do a long and time consuming ritual every time you leave the house, you might just decide it's easier to stay indoors. But avoiding things can have a major impact on your life.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

There are no expected impairments to communication however the person may struggle to engage due to anxiety. Concentration may be poor as the PIP assessment is an anxiety provoking situation so stress will be increased and as such so may the obsessions and compulsions. Be direct, empathetic and professional.

Parkinson's

Parkinson's

Overview of the health condition or disability



What is the condition usually called?

Parkinson's



Are there any alternate names?

- Parkinson's Disease



What is the generally preferred term when referring to someone with this condition?

Parkinson's

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes

Impact can vary from day to day and from hour to hour depending on when medication was taken.



What aspects of daily living can be worse and what might be constant?

What aspects of daily living can be worse and what might be constant? Swallowing problems can make eating difficulty. It can be difficult to be understood as voice gets very quiet. Most aspects vary as freezing can occur.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

Dressing, Washing, bathing, cooking, cleaning, writing, speaking, walking, shopping, toileting, eating.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

All of the above. How long it takes to complete a task, reliably and repeatedly, is there things they can do at one point of the day that they cannot do at another.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

It is more than just a movement disorder – the effects of more than 40 non-motor symptoms are often neglected.

Remember that with Parkinson's everyone is different and will respond to treatment differently. Not everyone will present with a tremor, for example. Areas which an applicant might find difficult to talk about include:

- Impulsive and compulsive behaviours such as obsessive gambling, or hypersexuality that can be a side effect of some Parkinson's medication
- Psychosis, hallucinations, acting out vivid dreams that can cause injury to self and bed partner
- Depression
- Incontinence
- The loss of cognitive functions such as memory and slowness of thinking
- The loss of facial expression and spontaneity of communication can be a cause of extreme misunderstanding
- Social issues, isolation, anxiety and loss of dignity

As the condition is progressive, care and support needs will increase. This may be difficult for the person to talk about, or they may have developed coping strategies to avoid undertaking tasks or may not recognise the extent to which they do have problems.

Tiredness and pain are often underestimated.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Pain is often overlooked. Freezing is often overlooked. Muscles become stiff. As the muscles in the face become stiff, people often look miserable when they are not.



How is it best to ask about these areas?

It is best to ask directly if daily living is affected by pain, freezing, restless legs, tremor etc. Use open questions to find out how they are able to complete a task, probe as to how they complete the task



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Reports from Parkinson's Specialist Nurse, Consultant, Speech Therapist and Occupational Therapist.

Presenting symptoms

Tremor, dyskinesia, speech problems and freezing.





Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Ask if they require assistance. Do not expect them to walk long distances. If given a drink, it should only be half full as tremor may mean that it could be spilt. Give them plenty of time to reply to questions.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Ensure that they are given plenty of time to reply. Do not rush an answer. Be close to them so that you can hear their reply.



Further reading:

Parkinson's UK website has literature which can be downloaded.

Psychosis

Overview of the health condition or disability



What is the condition usually called?

Psychosis. Although it can be considered a condition it is really a set of symptoms. Psychosis can occur on its own but people can also experience it as part of a different condition.

For example, psychosis is usually the main symptom within schizophrenia, but within that there are there also many different types schizophrenia. Similarly, psychosis can also be linked to a variety of affective disorders, such as bipolar disorder.



Are there any alternate names?

- Psychotic
- Psychotic episode
- Psychotic break
- Psychotic symptoms
- Psychotic experience
- Panic disorder
- Phobias such as social anxiety disorder/social phobia
- Post-traumatic stress disorder (PTSD)
- Obsessive-compulsive disorder (OCD)



What is the generally preferred term when referring to someone with this condition?

We would suggest 'someone experiencing psychosis.' People who are experiencing psychosis may prefer other terms, there is no one term that people who experience psychosis prefer to have the condition described as, but it should be borne in mind that all the terms above are associated with significant stigma.

Referring to someone as psychotic should be avoided.

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes

The condition varies, but these variations can on occasion last a long time.



What aspects of daily living can be worse and what might be constant?

People who experience psychosis may experience it only once for a short time or it may be part of a longer term illness (eg schizophrenia, bipolar disorder, schizoaffective disorder).

In general they will have periods of wellness or times where the other symptoms of their illness are more prevalent. This will probably change the way their daily life is affected.

Both negative and positive symptoms can make 'normal' daily life almost impossible. Even when symptoms are absent, the threat of them returning is constant, and individuals with psychosis know that if they do return, the impact will be huge, which means that life without symptoms is affected.



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

People have hallucinations (hear or see things that do not exist), or delusions (believe things that are clearly outside of what is expected of someone of their culture). These symptoms will vary considerably from person to person and the condition is likely to fluctuate. Both of these make focusing on daily activities very challenging and in some cases impossible. Such an example would be trying to shop whilst a voice is telling a person to kill themselves. These are known as 'positive' symptoms, because they change behaviour, and can be identified and described.

Other people will display 'negative' symptoms, such as a lack of energy, motivation, or depression, meaning getting out of bed or cooking a meal can be extremely difficult or impossible. These cases are harder to identify, because the person in question does not visibly display symptoms. They may also not personally associate these symptoms with their condition. A person may appear disinterested or uncooperative, when these are actually manifestations of their condition. Both positive and negative symptoms could make things such as keeping appointments difficult.

We have made some suggestions in line with the PIP criteria.

Preparing/food managing nutrition.

May be difficult due to getting 'distracted' by hallucinations or refusing to eat due to delusions. Cognitive impairment also affects the ability to prepare food and take it in.

Managing therapy/monitoring health condition.

When experiencing psychosis it is common for people to lack insight into their condition. They are unlikely to believe anything is wrong so may stop taking medication/attending other therapy. Their condition may deteriorate very quickly.

Washing and bathing.

As with preparing food/managing nutrition someone might lack motivation/refuse to wash and bathe appropriately.

Dressing and undressing.
May dress inappropriately.

Communicating verbally.
Cognitive impairment may make communication difficult. Hallucinations and delusions may cause someone to use a communication style that cannot be understood by others (eg speaking in tongues.) May not be able to properly interpret others due to delusions.

Reading and understanding signs, symbols and words.
May be difficult due to impaired cognitive function.

Engaging with other people face to face.
Likely to be very difficult. Others may find the persons thoughts and behaviours unacceptable. Delusion can often be paranoid and result in a fear of others.

Making budgeting decisions.
May be made more difficult due to cognitive impairment. Delusions and hallucinations can be about money which can cause the person to make unwise decisions they wouldn't otherwise make.

Planning and following journeys.
May be made more difficult due to cognitive impairment. Paranoid delusions may mean making journeys will cause distress.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Side effects of medication. Antipsychotics have a lot of physical and psychological side effects which can make daily life more difficult including:

- stiffness and shakiness
- akathisia
- tardive dyskinesia
- sexual dysfunction
- slowness
- weight gain
- hypotension
- anticholinergic side effects

With permission, opinions of carers and family members should also be sought given the additional insight they may be able to provide.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

People may think that someone with a diagnosis of psychosis or schizophrenia will look 'mad' in some way. Usually people with these diagnoses appear no different from anyone else. This can cause much misunderstanding, and the idea that nothing is really wrong.

Claimant may lack insight and not believe they are experiencing any symptoms.

Positive symptoms can be very hard to describe due to stigma and shame. Negative symptoms can be impossible to describe because people are unaware that they exhibit them due to their condition.



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Negative symptoms and cognitive impairment as these are less 'visible' symptoms.



How is it best to ask about these areas?

Professionals asking the questions need to understand the condition and demonstrate it in their questions. They should also be non-judgemental and reassuring and also be aware that individuals with the full range of symptoms may attempt to hide them.

Ask carers/health professionals as they can be more realistic about the illness.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Evidence from an expert in the diagnosis and management of the condition, and someone that has dealt with the person in question before and seen them when they are ill, should be sought. In some cases this will not be a GP.

Presenting symptoms



Hallucinations, delusions, cognitive impairment.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

This will vary from person to person.

There should be no suspicion that the person being questioned is being disingenuous in their answers or the difficulties they have in responding to questions.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

Be non-judgemental, if someone is experiencing hallucinations/delusion is experiencing something that is very real to them so trying to argue or rationalise that they are not is not appropriate.



Further reading:

Rethink Mental Illness psychosis factsheet:
www.rethink.org/resources/p/psychosis

British Psychological Society, Understanding Psychosis and Schizophrenia
www.bps.org.uk/system/files/Public%20files/aa%20Standard%20Docs/understanding_psychosis.pdf

Post Traumatic Stress Disorder

Post Traumatic Stress Disorder

Overview of the health condition or disability



What is the condition usually called?

Post Traumatic Stress Disorder



Are there any alternate names?

- Shell shock
- Soldiers heart
- Battle Fatigue
- Combat stress
- Post - traumatic stress syndrome (PTSS)



What is the generally preferred term when referring to someone with this condition?

PTSD – Post Traumatic Stress Disorder

Today, the term PTSD can be used to describe the psychological problems resulting from any traumatic event.

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes



What aspects of daily living can be worse and what might be constant?

- Cooking
- Eating
- Washing
- Dressing
- Sleeping
- Socialising
- Making a journey alone

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

- Panicking when reminded of the trauma
- Being easily upset or angry
- Extreme alertness
- A lack of or disturbed sleep
- Irritability and aggressive behaviour
- Lack of concentration
- Being easily startled
- Self-destructive behaviour or recklessness.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

- Social
- Journeys
- Personal hygiene
- Cooking/Eating
- Relating to others (Gender, race , religion)
- Motivation
- Overcoming fears

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

- Socialising
- Going out
- Going out alone
- Feeling vulnerable in different surroundings
- Mixing with other people (gender, region, race)
- Sleeping / nightmares



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

- Reliving aspects of the trauma:
- Vivid flashbacks (feeling that the trauma is happening all over again)
- Intrusive thoughts and images
- Nightmares
- Intense distress at real or symbolic reminders of the trauma
- Physical sensations, such as pain, sweating, nausea or trembling.
- Avoiding activities such as using public transport



How is it best to ask about these areas?

The Health Professional should never ask the Claimant to describe the trauma and this can be a trigger for the above. PIP is an assessment of current function and it is not relevant or necessary to explore what caused the symptoms.

Instead they should focus on how PTSD affects their ability to function in relation to the activities

Using a mixture of open and closed questions

What do you.....

When do you

Why

How

Where and who



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

- Report from a CPN



Presenting symptoms

- Severe anxiety
- A phobia
- Depression
- A dissociative disorder
- Suicidal feelings.
- Hypervigilance



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Never ask them to relive the trauma.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

- They need to be given time to respond
- Patience
- Empathy
- Help them keep them on track



Further reading:

www.mind.org.uk/information-support/types-of-mental-health

Rheumatoid arthritis (RA)

Rheumatoid arthritis (RA)

Overview of the health condition or disability



What is the condition usually called?

Rheumatoid arthritis (RA), a type of inflammatory arthritis (IA). Occasionally people with (adult) juvenile idiopathic arthritis (JIA) will describe themselves as having RA.



Are there any alternate names?

See above



What is the generally preferred term when referring to someone with this condition?

We do prefer to say 'people living with rheumatoid arthritis' to 'sufferers' or 'patients'.

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes, significantly.



What aspects of daily living can be worse and what might be constant?

RA is a fluctuating condition. Even when optimally controlled by medication, an underlying level of the disease tends to be there all the time, but the degree of symptoms varies. Stiffness tends to be worst in the morning, when it is common to take more than half an hour to relieve. Flare ups of the condition, when particular joints are swollen and tender, can come at any time, but more commonly when the condition is poorly controlled. These can last for days or weeks.

If someone with RA has had a joint replacement then the limitation to function will be constant regardless of condition state and this should be considered.

Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

Hands and feet are the most commonly affected areas in someone with RA, and the stiffness associated with the condition is worst in the morning or after being still for long periods (e.g. when travelling). Getting dressed in the morning and getting up from sitting or lying down can therefore be particularly difficult. Grip can be impaired, making activities that require fine motor skills challenging.



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

- The variable nature of the condition, both day to day and during a single day.
- The effects of fatigue on doing activities for long periods
- Repetitive activity can be difficult. A task could be performed once, but might not be possible to do multiple times or might cause extreme tiredness and subsequent need to rest later in the day.
- Common effects on mental health, such as impaired cognitive function and depression, due to pain and fatigue.
- Regularity and length of flare ups e.g. how many days are 'lost' in an average month.

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

People with RA will often live with long term pain and problems with function. They will therefore often have a high pain threshold and may have adapted the way they do daily tasks, sometimes without noticing, so may underestimate the difficulty with which they do tasks.

A common example could be that someone says they dress themselves, but have stopped buying clothes with buttons, as they can't do them up, might take a long time and might have a partner helping them (e.g. with buttons, zips or bra strap).



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

The biggest misunderstanding with RA is the word 'arthritis'. Arthritis is a term more commonly given to osteoarthritis, which is caused by wear and tear, is not systemic like RA and tends to affect less joints. It is therefore crucial that the condition is not shortened to 'arthritis' by the assessor, and that they understand this is an autoimmune condition, so usually affects multiple joints and has systemic (affects whole body) symptoms, such as fatigue and flu-like symptoms.

Fatigue is often underestimated and is a common and debilitating symptom of RA.

RA is often an 'invisible' disease. Unless there are obvious deformities, someone with RA can look perfectly 'normal' despite underlying levels of pain, stiffness, fatigue and even damage etc.

Walking aids can be difficult for someone with RA, due to hands being the most commonly affected area of the body. Someone with this condition may therefore not have a walking aid, not because they don't need it, but purely because it would be too painful to put that pressure on their hands.



How is it best to ask about these areas?

Ask directly about symptoms experienced by the individual, rather than going too much on how they look.

Ask what type of day the day the person is having, i.e. is it a 'typical' day, or particularly good/bad? Are they having a flare at the moment? Have they recently had a steroid injection, which could make their condition artificially good that day?



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

RA is a specialist condition, treated in secondary care. A rheumatologist, rheumatology specialist nurse or OT etc is therefore likely to know more about the patient's condition than a GP, who may not be involved in their care.

Presenting symptoms



- Pain
- Stiffness (especially if early in the morning)
- Swollen joints (not always visibly swollen)
- Fatigue
- Flu-like symptoms

Please note, due to the variable nature of this condition, some or all of the above may not be present during a face-to-face consultation, so it is important to ask what type of day the person is having and to talk to them about what a typical day is like, rather than putting too much emphasis on how they are on this particular day at this particular time.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

Standing for long periods of time or using stairs may be difficult, so should be avoided where possible. Basic facilities in a consultation centre should be pointed out, but in terms of the level of assistance needed or that should be offered, this would have to be decided on case-by-case, as the condition varies greatly between individuals.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?



Further reading:

NRAS on how to claim PIP inc tips etc for people with RA:

www.nras.org.uk/publications/how-to-claim-personal-independence-payment-pip

NRAS on being newly diagnosed with RA inc much relevant info:

www.nras.org.uk/publications/newly-diagnosed-a-guide-to-your-next-steps

Spinal Cord Injury

Spinal Cord Injury



Overview of the health condition or disability



What is the condition usually called?

Spinal Cord Injury



Are there any alternate names?

- Paraplegic
- Tetraplegic
- Quadriplegic
- Complete Spinal Cord Injury
- Incomplete Spinal Cord Injury
- SCI



What is the generally preferred term when referring to someone with this condition?

A person with a spinal cord injury

Commonly reported variability in functional restrictions



Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

No

This is not a fluctuating condition but the symptoms can vary



What aspects of daily living can be worse and what might be constant?

This is not a fluctuating condition



Common areas of daily life where functional restriction occurs



What areas of daily life will a person with this particular health condition or disability find challenging?

- Loss of mobility
- Loss of sensation
- Double incontinence
- Increase pain & spasms
- Skin Viability
- Neuropathic pain
- Temperature regulation
- Mental Health



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

- Management of Bladder and Bowel
- Frequency of urinary tract infection
- Autonomic Dysreflexia on injury of T6 and above

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

- Management of Bladder and Bowel
- Autonomic Dysreflexia on injury of T6 and above
- Pain levels
- Mental health



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Claimants have normalised their condition but are still at risk of falling, burning themselves etc.



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

- Consultant or GP to confirm injury
- Care Plan or family member to confirm care needs for daily living
- Sickness Record from employee
- Witness statements from carers

Presenting symptoms



- Anxiety
- Embarrassment
- Stress
- They might not have verbalised their condition and the effects that it has on their daily life or their family.
- Normalising or underplaying their condition

Etiquette and common courtesies



It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

- All staff should have Disability Awareness Training
- Keep the interview claimant focused

Stroke



Overview of the health condition or disability

 *What is the condition usually called?*

Stroke.

A stroke is a brain attack. It happens when the blood supply to part of the brain is cut off.

Most strokes are caused by a blockage cutting off the blood supply to the brain. This is an ischaemic stroke. However, strokes can also be caused by a bleeding in or around the brain. This is a haemorrhagic stroke.

A transient ischaemic attack or TIA is also known as a mini-stroke. It is the same as a stroke, except that the symptoms last for a short amount of time and no longer than 24 hours. This is because the blockage that stops the blood getting to the brain is temporary.

 *Are there any alternate names?*

- Cerebral Vascular Accident - CVA
 - Brain Attack
 - Clot or bleed in the brain
 - Subarachnoid Haemorrhage
 - Trans ischaemic attack
- TIA (mini stroke with effects lasting no more than 24 hours)

 *What is the generally preferred term when referring to someone with this condition?*

Stroke Survivor or a person affected by stroke

Commonly reported variability in functional restrictions

 *Do people with this particular health condition or disability find its impact on daily life can vary from time to time?*

Yes and No

 *What aspects of daily living can be worse and what might be constant?*

All strokes are different - Many people have problems with extreme tiredness after a stroke. This is known as post-stroke fatigue. Unlike usual tiredness, fatigue doesn't always improve with rest and it isn't related to how busy or active you've been - therefore mobility, ability to think and carry out activities of daily living may vary.



Common areas of daily life where functional restriction occurs

 *What areas of daily life will a person with this particular health condition or disability find challenging?*

Blood carries essential nutrients and oxygen to the brain. Without blood the brain cells can be damaged or die. This damage can have different effects, depending on where it happens in the brain. A stroke can affect the way the body works as well as how you think, feel and communicate.

All strokes are different so for some people the effects may be relatively minor while others may be left with more serious long term problems. A stroke can affect the way the body functions and affect activities of daily living. Although all strokes are different, there are some common physical problems that many people experience which are challenging

- problems with movement and balance: many people experience muscle weakness or paralysis after a stroke, which can affect mobility and balance.

This usually happens on one side of body and can also cause a lot of pain and discomfort. This affects mobility, washing, dressing, preparing food, maintaining a safe environment, increases risk of falls

- problems with vision
- problems with swallowing
- problems controlling bladder and bowels
- excessive tiredness.



But there are other effects that you can't see - Some of the 'hidden' effects of stroke include:

- Problems with communication: many people have difficulty with speech and language after their stroke. A common communication problem, which affects around one third of stroke survivors, is aphasia. People with aphasia find it difficult to speak and understand what other people are saying to them, as well as reading and writing. Dysarthria happens when you're not able to control the muscles in your face, mouth and throat very well, so it's difficult to speak clearly. This can mean that your speech becomes slurred or slow or that your voice sounds quiet. Apraxia of speech is when you can't move the muscles in your face, mouth or throat in the order you need to when you're speaking. This can make it difficult for other people to understand you.
- Problems with memory and thinking: it's very common to find that short term memory and concentration is affected by stroke, but it can also affect other thinking processes as well, such as problem-solving, planning and finding your way around. May affect ability to take medication correctly, mix day and night up etc
- Changes to emotions: a stroke has an emotional impact, which can lead to problems like depression and anxiety. It can also make it more difficult to control your emotions.
- Changes to your behaviour.
- Increased stress for carers and family members

For further details please see website: stroke.org.uk



Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

Please see above & see website for further information if needed www.stroke.org.uk

Common misconceptions about the health condition or disability



What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

Behavioural issues, emotional issues, ability to cope, sexual & relationship issues, continence issues, cognitive issues



What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

Aphasia and communication difficulties are often thought to be memory and cognitive issues. Although some people assume that they do, communication problems do not affect your intelligence ... they simply have problems with the process of speaking and understanding language. Please see above re The Hidden Side of Stroke and see website for more information www.stroke.org.uk



How is it best to ask about these areas?

Just be open and honest. A stroke survivor may have communication difficulties and difficulty in understanding questions - so may need support from a family member, a Speech and Language Therapist or a Stroke Association Coordinator when being asked questions. Speak slowly and clearly using short sentences, wait for a response without interrupting - check that Yes & no responses are reliable, use gestures. For more information see stroke.org.uk/aphasia



What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

Reports from Stroke Consultant, Occupational therapist, physio, GP

Presenting symptoms



May have poor mobility, be in pain, have difficulty understanding or may have communication issues. They may have emotional lability - a term used to describe a tendency to laugh or cry unexpectedly at what might seem the wrong moment. Poor vision.



Etiquette and common courtesies

It's important to understand the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

No need to treat differently. Be led by the stroke survivor. May need to offer support with communication should the stroke survivor have communication difficulties.

Recommended communication approach to a claimant at a face-to-face consultation



What are the best communication approaches necessary to engage someone with this health condition or disability?

If a person has communication issues ... Speak slowly and clearly using short sentences, wait for a response without interrupting – check that Yes & no responses are reliable, use gestures. Stroke survivors may be able to communicate with pen & paper, pictures etc.
For more information see stroke.org.uk/aphasia



Further reading:

See Stroke Association Website:
Stroke.org.uk

Stroke Association helpline:
0303 3033 100

