

The **Thalidomide** Trust

Personal Independence Payment (PIP) Pack

Welcome to the PIP pack. This information is designed specifically to help beneficiaries of the Trust with their PIP applications. Getting the application form right – i.e. providing enough good information about your condition, and then confirming that information at the assessment, is absolutely essential to a successful application for PIP.

There is a wealth of good quality general information available about PIP, particularly the [Disability Rights Guide to claiming PIP](#). The information contained in this PIP Pack however focuses on the experience of Thalidomide affected people and their individual needs.

Contents of this PIP pack:

- Section A** - **Introduction to the PIP process**
- Section B** - **Case Studies**
- Section C** - **For people you are asking to write evidence for you**
- Section D** - **A guide to making a claim**

Section A

What is PIP?

PIP stands for **Personal Independence Payment** and it is the name of the new benefit that has been introduced to replace Disability Living Allowance (DLA).

Basic Information on how PIP works, eligibility and payment levels can be found on our website <https://www.thalidomidetrust.org/money-matters/benefits/pip/>

The PIP Process

If you are already receiving a fixed or indefinite award of Disability Living Allowance (DLA), you do not need to apply for PIP. You will be contacted by the DWP and invited to make a new claim for PIP.

If you have never applied for or been awarded DLA, but feel that you may now be eligible, you will have to make a new claim for PIP by telephoning the DWP and you will then follow the process from stage 2.

Stage 1 – Notification by the DWP that you are being moved to PIP

Once you receive your letter from the Department of Work & Pensions (DWP), you have 4 weeks to contact the DWP on the number provided and provide the relatively straightforward information requested in the letter.

We would like to know when you have been contacted to move to PIP, even if you feel that you don't need any help at this stage, it is useful for us to understand how many people are being affected by the changes. Please email michelle-jane.robinson@thalidomidetrust.org to us to let us know.

Stage 2 – Completing the form entitled: 'How your disability affects you'

Approximately 2 weeks after you have responded to the first letter, you will receive a form entitled: 'How your condition affects you'. You have **one month** to complete and return this form and it is important to remember to keep a copy of the form once you have completed it. This is so you can take it to your medical assessment or refer to it later on, if your application is contested.

It is very important to complete this form as fully and clearly as possible. This is the most important part of the process along with gathering any supporting evidence.

If you are unsure or need help completing this form there are a number of places you can get help. The Citizens Advice Bureau (CAB) has a good online tool:

<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/help-with-your-claim/fill-in-form/> and can also provide help face to face. You will need to call your local CAB and make an appointment, so do this in good time.

Click here to find your local CAB: <https://www.citizensadvice.org.uk/>

If you would like more advice on the above please contact us by e-mailing michelle-jane.robinson@thalidomidetrust.org. We can discuss your form with you and signpost you to a local advice service.

We can also put you in touch with a beneficiary volunteer who will help you make sure you fill the form in as thoroughly as possible.

We have put together some **case studies** from other beneficiaries who have been through the PIP process, to give you some idea of how to provide the information on the form and evidence your difficulties. These are just examples to help you think about your own problems, they may not all be relevant to you and you may have more to say about your own problems. However, they will help you understand how to think about the descriptors:

Case Study 1 – Upper limb and eyesight affected

Case Study 2 – Upper limb and back affected

Case Study 3 – Upper limb affected

Case Study 4 – Hearing impaired

Case Study 5 – Lower limb affected

What are the Descriptors?

The PIP descriptors include 10 areas of everyday living of activities, and 2 aspects of mobility activity. Each of these descriptors is assessed by the DWP using a scoring system. To get an award of the daily living component you need to score 8 points for the standard rate 12 for the enhanced rate. To get an award for the mobility component you need to score 8 points for standard rate and 12 points for the enhanced rate. The person assessing your application will be looking at the detail in your form and judging it, along with the evidence you provide.

Supporting Evidence

You have the opportunity to send supporting evidence to back up the information you have provided in the form. This will not be taken into account unless you disagree with the outcome of the assessment, however it is useful to get it together at this stage while you are focused on producing your information.

The extra information we suggest you gather could include:

- A medical report from any specialist you have been seeing. They may charge you for this.
- Information that confirms any adaptations you have made to your home or car – e.g. invoices
- A supporting letter that provides information about how your disability affects you. The Thalidomide Trust can provide this for you, or you may have someone you see regularly relating to a long term condition who would also provide this – a physiotherapist for example.
- Letters confirming your appointments with any therapists you see regularly.

If you need more time to fill in your form, don't panic. You should contact the PIP claim line immediately and ask for an extension (telephone: 0800 9172222 or textphone: 0800 917 7777 8am to 6pm Mon to Fri). If you have a good reason, they'll agree a new deadline over the phone. If you are worried about time and need help asking for an extension, contact michelle-jane.robinson@thalidomidetrust.org for help.

Stage 3 – The Assessment

In some cases DWP assessor, will decide if they have enough information to make a decision based on the information in your form and supporting information alone. We are keen to know if this happens to you – please let us know by e-mailing michelle-jane.robinson@thalidomidetrust.org

If the DWP need further information from you to make a decision about your claim, they will then instruct one of two contracted assessment companies, Atos or Capita to further assess you. In most cases you will be contacted by one of these organisations and be invited to attend a face to face assessment. This will be held at an assessment centre that is relatively local to where you live. You are able to take someone with you to the assessment and bring along a copy of your application form so you can refer to this.

The person carrying out the assessment will have all the information from your form. It is **essential** that at the assessment you repeat and reinforce this information as that is what the assessor is looking for. The assessor is there to observe your situation in line with the descriptors and ask questions to confirm how your disability affects your day to day activities in the following areas:

Ten areas of **daily living activity**:

- Preparing food
- Taking nutrition
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face to face
- Making budgeting decisions

Two areas of **mobility activity**:

- Planning and following journeys
- Moving around

The DWP assessor will utilise the information provided by the professional, who has met you, to make their final decision. Ultimately the power of award and decision lies with the DWP.

Requesting a Home Assessment

In some circumstances you can request that assessment takes place at your home, particularly if you can evidence that you have significant difficulties travelling and moving around due to your disabilities or anxiety for example and would have great difficulty getting to the assessment centre.

Evidence will need to be provided from a GP or other healthcare professional who is treating you that you are unable to travel due to health grounds

Preparing for an Assessment

The assessment is a key part of the process and it is helpful to understand the criteria that the assessor will use and how you can help them understand the impact your disability has on you.

People have told us that they find the assessment a difficult experience because it forces them to focus on the negatives and all the things they can't do. Many beneficiaries cope very well on a day to day basis, have a very positive outlook towards their abilities and hate to define themselves as disabled. However it is very important, that the assessor understands what life is like for you most of the time to ensure to award you the correct number of points.

There are two key areas – how often you have difficulty carrying out an activity and how reliably you can carry it out.

The assessor will ask about how **often** you experience the difficulties with the activities of daily living that you have described in your form. . The important point for the assessment is to be clear whether you experience each difficulty on **more than half** of the occasions that you undertake that task within any set period, which may be daily, a week, a month, or a year.

The assessor will award you points based on whether you can complete a task within a descriptor **RELIABLY**. The “Reliably” test is very important and means:

Safely

- You have to be able to manage an activity in a manner that is unlikely to cause any harm to yourself or anyone else. Harm doesn't have to occur, but if it is likely to occur then you are not able to complete a task “**reliably**”.

For example – if you can make a sandwich (or cup of tea) and experience numbness in your hand which means that there is a high risk that the knife (or kettle) might slip and you could cut yourself– you cannot prepare food “safely”.

Repeatedly

- If the effort of completing the activity makes it hard for you to repeat that particular task or prevents you from completing other tasks, e.g. due to a combination of pain and fatigue, you are not ‘**reliably**’ able to do it.

For example – if you can go to the toilet independently in the morning using the commode, (or walk 50 metres) but cannot do it later in the day as your pain and tiredness is worse, then you cannot do it “repeatedly”.

In a reasonable time

- If a person did not have the same mental or physical condition as you, then how long would they take to do that task? If you would take more than twice as long as this, then you are not achieving that particular descriptor ‘**reliably**’.

For example – if you can manage to shower and dress yourself but it takes more than twice as long as someone who does not experience the same difficulties as you in managing this task, then you cannot do it “in a reasonable time”.

To an acceptable standard

- If you perceive that you can manage a task and actually see it through but are unable to carry it out effectively and thoroughly then this has not been achieved ‘**reliably**’. This is because it has not been carried out to an ‘acceptable standard’.

For example – if you can wash yourself but can't reach your hair and certain parts of your body thoroughly even with using an aid, then you cannot do it “to an acceptable standard”. You may be able to squirt the shower gel on your chest and then you leave the water to rinse the gel, but this not getting thoroughly cleaned.

Stage 4 – Notification of the Decision

You will be notified of the decision by letter usually within 4 weeks of the assessment. This will tell you which element of PIP you have been awarded and at what level.

Please let us know by e-mailing michelle-jane.robinson@thalidomidetrust.org the outcome of your PIP application for our records and if you are unhappy with the decision, contact us for help with what to do next.

Stage 5 – Mandatory Reconsideration

If you think the Department of Works and Pensions (DWP) has made the wrong decision about your claim for PIP, and you did not get the award that you think you were entitled to, you can challenge the decision by asking the DWP to look at their decision again. This is called a 'mandatory reconsideration'. This is the process whereby you formally ask the DWP to look again at their decision and can provide further evidence or information to help your case.

If you wish to appeal at a later date, you **MUST** have gone through this process first.

Click here for more information <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/appeals/mandatory-reconsideration/>

If you would like some help or advice at this stage, please contact us by e-mailing michelle-jane.robinson@thalidomidetrust.org

Stage 6 – Appeal

If you are not happy with the outcome of the DWP's reconsideration, then you can appeal to the First Tier Tribunal in writing.

The Tribunal may be able to make a decision based on your written appeal, or you may be required to attend in person. Click here for more information on Appeals <https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/appeals/apply-to-tribunal/>

If you are considering an appeal and feel you need some help, please contact Michelle Robinson on 01480 474074 or e-mail michelle.jane.robinson@thalidomidetrust.org to talk about the help that is available.

Section B

Case Study 1 - Upper limb and eyesight affected

ACTIVITY	EFFECT ON ME
Cooking/preparing food	<p>Cooking: my condition doesn't allow me to cook, and this cannot be overcome with aids. Appliances like kettles and microwaves are particularly dangerous for me to use because of risks of spills and scalding due to upper limb and vision impairments.</p> <p>PAs assist me three times a day due to not managing to cook food safely; I am at risk of harm, burns/scalds through not being able to manage lifting pots, pans as unable to grip properly. I have a PA to assist me with these tasks. I am unable to use a microwave safely as in the past I suffered burns.</p> <p>The local authority have recently reviewed my care plan with an up to date review on the 17.03.16 (see enclosure 002). I have had the same care plan for 10 years; it enables me to maximise my independence whilst balancing the risk of harm to my physical, social, emotional wellbeing.</p> <p>Making snacks I find difficult due to issues with retrieving items from the fridge, it is hard for me to reach and grip, my left hand is particularly weak. It causes my back considerable pain to bend or stretch over to manage tasks that are below or above waist height. Sandwiches take a very long time to make as I have difficulty coordinating my hands to use sharp knives SAFELY. Also due to being registered blind I can't see properly. Poor dexterity and eyesight is why I have been assessed by the local authority as needing a PA to assist me with making snacks and meals. I am unable to complete making a sandwich in a REASONABLE TIME and REPEATEDLY, buttering back and forth is a real effort, I strain to manage this physically, bending over repeatedly causes back pain. I would have to pause, straighten up and start again.</p> <p>Reading labels to determine a use by date is a hazard due to no right eye and poor vision in left eye registered blind. Can't ensure eating food SAFELY that has not gone off, although I can smell, you can't always rely on one sense to determine food viability (salad leaves or any foodstuff bearing minor signs of mould).</p>
Eating and taking nutrition	<p>I need to use an aid or appliance to be able to take nutrition and have assistance to be able to cut up food.</p> <p>Cutting tough foods, peeling food, I can't manage safely as I can't see to coordinate the knife properly. If eating fish, someone takes bones out as can't see due to vision difficulties. Poor dexterity and strength, combined with poor eyesight make this impossible.</p> <p>Eating a burger in a bun is difficult, although I would ask for help so the burger doesn't fall out. Also, cutting food for me takes longer than a REASONABLE TIME.</p> <p>I drink through a straw as it causes me pain to lift a glass and would take longer than a reasonable time to struggle to lift and put a cup/mug down on a surface.</p>

	Throughout the day I have a PA at intervals to assist me with the preparation, shopping for and eating food. Time required: (15 mins breakfast, 15 mins lunch, 30 mins dinner) approximately 7 hours per week.
Managing therapy/monitoring health condition	<p>I need supervision, prompting or assistance to be able to manage medication or monitor a health condition.</p> <p>Daily regime - unable to open packaging and need PA assistance: I cannot read labels, and need a PA to put the tablet or meds into a shot glass. I tip back the shot glass and swallow a tablet/drink medicine with a straw. Need assistance to administer as also unable to get meds out of packaging and read if I have the right product. Tiny tablets are hard to see and take. Can't manage this task to an ACCEPTABLE STANDARD or SAFELY. Unable to use a dosette box.</p> <p>Creams applied by PA, unable to reach and stretch to apply to an acceptable standard on my body (prescribed cream see meds list 007 prescribed Daktacort cream and Hibiscrub solution for use on the back area). Used daily. PA (15 mins x 2 a day. 30 minutes x 7) - 3.5 hours per week.</p> <p>Regular massage therapy (deep tissue) is required for musculo-skeletal alignment and management of chronic pain. This is paid for privately and usually includes at least two one-hour sessions per week delivered at home.</p>
Medication	
Washing and bathing	<p>I cannot wash and bathe at all and need another person to wash my entire body.</p> <p>Need assistance to shower; I wouldn't be able to do so to an ACCEPTABLE STANDARD and safely. Need to use my upper limbs to support me in the shower as no room for a shower chair. PA manages all of this task. Can't reach to wash all areas of my body. I require help to dry myself too as unable to manage this. I have especially selected shower controls so I can adjust temperature and turn water on and off SAFELY. The choice of shower controls is a practical rather than an aesthetic consideration (PA assists 30 mins x7 days so 3.5 hours per week)</p> <p>A bathroom sink is set at my height with a long lever tap so I can wash my face and clean my teeth in the morning and brush my teeth before I go to bed. I use an electric toothbrush as I lack sufficient dexterity to use a regular toothbrush.</p>
Going to the toilet Managing toilet needs and continence	<p>I need assistance to be able to manage my toilet needs. I am unable to clean myself and dress and undress before and after.</p> <p>At home I use a Clos-o-Mat and a Geberit bidet toilet for personal hygiene. Outside the home I use an Aquarius Hygiene Porta-Bidet to assist with cleaning. This takes longer than a person without a disability, so I am unable to manage this in reasonable time. However, when out I would need assistance with fastenings on trousers depending on what clothing I wear as I am unable to manage this to an acceptable standard.</p> <p>IBS (see meds list 007 Loperamide taken daily) – I need to find a toilet at short notice, can have accidents as not get to the toilet in suitable time, i.e. one with a RADAR key. Need the extra space to set up the Porta-Bidet. This is used when I go for an overnight stay or out for a day.</p>
Dressing/undressing	<p>I cannot dress or undress without help.</p> <p>Morning routine: I go downstairs with dressing gown on, belt has to be fastened by my PA. I have breakfast then go with PA upstairs who helps me get dressed; assistance is needed with every item of clothing. I cannot do this myself to an acceptable standard and in reasonable time. Need full assistance with dressing.</p>

	<p>Four days a week on average I need to wear suitable work clothes and need assistance to get out of this more formal wear. However, loose-fitting clothes, I am able to take off by myself. I have to wear slip-on shoes.</p> <p>Always need help to put on and take off outdoor clothing, unable to put arms in coat and zip up my coat, otherwise I would be unable to stay warm. Twisting to get in and out of coats etc. is really difficult, causes pain and I can't reach to manoeuvre my arms in outdoor jackets. Can't manage to an acceptable standard and safely, i.e. risk of harm from catching cold, getting wet and getting ill in poor weather.</p>
Communicating verbally	
Reading and understanding signs and symbols	<p>I need to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information.</p> <p>Limited reading is possible with special glasses. My PA at work assists me to read documents and types for me. Cannot read standard print, need written communication in electronic format, if not, then someone will need to read it to me. Large print is readable also i.e. my care plan is in large print (see 002). Reading long documents or books is done using either audiobooks or text-to-speech software or human assistance.</p> <p>For work, I have a large screen computer 27" and use the built-in text-to-speech technology and screen magnification in order to make print accessible. I also require a trackball mouse – don't have to move arm backwards and forwards or right to left (use of a standard mouse causes repetitive pain in arms, shoulder and neck). I also use a large print keyboard. Even then, only limited typing is possible.</p> <p>I need assistance to read signs and symbols when out to understand danger implications and to be correctly orientated e.g. X-ray dept. at hospital. The print on medication and food labels is too small to read.</p>
Meeting people engaging with others face to face	<p>I need social support to be able to engage with other people from a person trained or experienced in assisting people to engage in social situations - i.e. a fully trained PA.</p> <p>I need support to mix with others which is necessary for both professional and personal interactions. Due to poor eyesight sometimes I miss social cues due to not being able to see detail on people's face. In unfamiliar environments I would need someone with me to assist in this area. Would not go out unless I had someone familiar with me or otherwise unable to attend.</p> <p>I have a PA at work to assist and also seek assistance from home PAs or a friend otherwise I wouldn't go out. I wouldn't meet people I know without someone with me. I would feel as though I was at an unfair advantage socially without assistance.</p> <p>I need assistance to locate people I'm due to meet as wouldn't be able to find them. I can't recognise their face as I can only see the outline of a person.</p> <p>I get severely anxious if can't find who I'm looking for. I will occasionally arrive extremely early for someone to have to find me. The prospect of going to events can be so overwhelming that it can put me off attending. If alone I wouldn't go at all. I wouldn't go to a music gig alone. I need assistance to go out and I struggle with anxiety over this more than 4/7 days.</p>
Going out	<p>I cannot follow the route of a familiar or unfamiliar journey without another person, an assistance dog or an orientation aid.</p> <p>My sight and upper limb impairment mean I am unable to use an orientation aid - it would be too dangerous. There is risk of falls, which also adds to anxiety. I had an unsuccessful trial with an assistance dog. I cannot use public transport.</p>

	I don't go out to familiar places without another person due to hazards like scooters, cycles on pavements, children etc. My PA points out obstacles, dangers on road, steps, kerbs etc. My PA drives my car.
Moving around	Walking is inhibited by poor vision, balance issues and fear of falls, the consequences of which can be extremely serious because of my upper limb impairments. I need to hold on to someone. I can walk more than 200m but need assistance and may move slowly. My PA walks next to me and will verbally guide me unless negotiating steps, when I will ask for their hand.
Additional information	When assessing this application for Personal Independence Payment, the compound effects of the impairments already described in the questionnaire have to be taken into account. Unfortunately, the whole is greater than the sum of the parts: for instance, having extremely poor vision (being registered blind) and having severely shortened upper limbs means that there is an exaggerated risk of falling due to poor vision and an enhanced risk of injury due to an inability to save oneself. There is a wealth of medical information that shows accelerated ageing among those disabled by the morning sickness drug, thalidomide. It is estimated by the Heidelberg University School of Gerontology that thalidomiders are accelerating their ageing by at least 20 years: the authors found advanced wear and tear on joints and other musculo-skeletal damage, internal organ damage (previously undiagnosed) and mental health issues resulting from a lifetime of living with complex impairments.

Section B

Case Study 2 – Upper limb and back affected

ACTIVITY	EFFECT ON ME
Cooking/preparing food	<p>Can't manage cooker to heat up porridge, unable to lift saucepan or stir without pain and don't have the strength. Can use microwave.</p> <p>Unable to cut crusty bread, so I can't have it, although I really love it toasted, because I can't use a sharp knife safely</p> <p>Unable to lift the kettle to make a cup of tea as don't have the strength or it causes pain. I have scalded myself with hot water trying to do this on three occasions. I use an aid to do this.</p> <p>I would like to eat more salad to help manage my weight but I can't cut it up. I can't chop veg properly at all as it is difficult, slow and dangerous. Poor dexterity and not enough pressure to manage task. Fearful of cutting myself as I have done this in the past, so I buy ready chopped vegetables.</p> <p>Unable to maintain a safe grip on a saucepan and lift it, or lifting the saucepan causes pain in shoulders and neck.</p> <p>I use special lightweight pots and pans</p> <p>I can heat up a meal in the microwave as long as not got a film lid as I cannot remove this.</p> <p>Today I couldn't open the microwave as not enough grip due to pain. I could do this 4 days out of seven but grip worse today</p> <p>Can't grip tins to open. Use an aid to manage this ok.</p>
Eating and taking nutrition	<p>My grip was poor this morning and I was unable to drink my hot tea safely. This happens about two mornings a week,</p> <p>My teeth are very painful as a result of my condition, so I can only eat soft food</p> <p>Some food I can't have as I can't cut it up to eat it.</p> <p>Went out for dinner, had to ask for food to be cut up for me.</p>
Managing therapy/monitoring health condition	<p>Physiotherapist has recommended hydrotherapy to manage my pain and help with weight loss. I wanted to go swimming today but unable to go alone as I need help to get out of pool due to ladder. When I go swimming I can't get my wet costume off without help. My GP has recommended swimming to help manage my weight.</p> <p>Attended counselling for anxiety. Having been seeing GP with anxiety and depression for 18 months.</p>
Medication	<p>Unable to open medication bottles for my regularly required medication (not PRN meds) I have an aid to do this.</p>
Washing and bathing	<p>Teeth, maintaining and manage dental care difficult, can't reach all teeth. I have bad teeth as a result which are painful. I have to go to the dentist every two months.</p> <p>Unable to wash and scrub body everywhere properly, only as far as I am able to reach with my shorter arms. Am limited to where I can reach. I have to put shower gel on haphazardly, i.e. squirt on chest and aim at stomach and let the soapy water from the shower run over all my body. Drying I wrap a towel around and have to pad my body against the towel and bed/chair. To dry, takes a long time to dry properly, more than twice as long as would be usually expected.</p>

	<p>Every 5-6 days, see the hairdresser to wash my hair as unable to reach to do this at all.</p> <p>I have lever taps at home, when I am out I am often to turn taps on as done up too tight due to grip being poor. Only this difficulty when I go out which is less than half the time spent at home.</p>
<p>Going to the toilet Managing toilet needs and continence</p>	<p>To manage to clean properly after the toilet, I need assistance to wipe where needed. However, I do not have this assistance and cannot reach to wipe so have to shower more regularly. Showering does not enable me to clean really effectively my intimate body parts. I spend a long time in the shower to enable the soapy water to rinse throughout my body to the optimum it can in this manner.</p> <p>I get very anxious about being able to clean myself if I need the toilet when I am out. This stops me going out.</p>
<p>Dressing/undressing</p>	<p>I do not wear a bra as I am unable to reach to manage the clasps at the back, If I had the assistance this task could be managed. I would feel better wearing a bra and less self-conscious. I am unable to lift regular jumpers over my head, I have my clothes specially adapted for me, especially those on my upper half i.e. my coat has been adapted. I am not able to do up or undo and buttons, belts or fastenings, including my coat. If I had assistance to do up my coat I would be able to go out in the cold weather dressed to a reasonable standard.</p> <p>I am unable to wear tights as unable to pull them up, just wear skirts and dresses without them.</p> <p>I need a shoe horn to take my shoes off 7 days a week.</p>
<p>Communicating verbally</p>	
<p>Reading and understanding signs and symbols</p>	<p>When the post arrives I can't pick it up or open it without an aid.</p>
<p>Meeting people engaging with others face to face</p>	<p>I avoid social situations as much as possible due to causing psychological distress to meet and engage face to face. I only go out if my sister will come with me and am very self-conscious about people staring at me. By the end of the day I am often so exhausted that I cannot socialise.</p>
<p>Budgeting decisions</p>	
<p>Planning and following journeys</p>	<p>I avoid public transport because I worry about being knocked. Also, I can't hold onto rails on public transport if no seat is available.</p>
<p>Moving around</p>	

Section B

Case Study 3 - Upper limb affected

ACTIVITY	EFFECT ON ME
Cooking/preparing food	<p>I am unable to prepare and cook a meal for myself from scratch, to do so would put me at risk as I would cut, burn or scald myself.</p> <p>As I cannot use my left arm and my right arm which has 3 fingers, as I suffer numbness and pins and needles and it is too weak to grip or hold implements. Therefore I cannot use implements to peel or cut, as I would cut myself if I carried out this task. I can no longer chop or peel even using aids as I would hurt myself.</p> <p>I do not have the strength in my wrist to lift pans or saucepans and I would burn and scald myself if I did. I have experiences of the frying pan falling off the hob onto the floor, which I cannot not bend down and pick up and I have also scalded myself emptying out boiling water from a saucepan.</p> <p>To stand in the kitchen at the hob is not only dangerous as explained above, but leaves me in excruciating pain and as it places more pressure on my already painful back and would be very tiring for me and would take me a lot more than twice as long as a non-disabled person to cook a meal.</p> <p>I do not cook or prepare any meals for myself, my daughter or a friend provides them for me to reheat, which I do using a microwave.</p> <p>I do not use the oven or the hob because it is too dangerous for me as I am at risk of burning myself and also I have forgotten to turn them off in the past and this causes me great anxiety.</p> <p>I use a small knife and fork – child size as the stem is smaller, adult size digs into the skin and makes it difficult to manoeuvre. Cannot open tins or packets.</p> <p>If a friend or family member has not left a meal, I use microwave meals, but have to be very selective as I cannot cut food myself. I cannot grip the knife to be able to cut through food and it is very painful on my hands and wrists to even try. I buy vegetarian food (for microwave) or for example macaroni cheese, as it is already small bite-sized food that does not require cutting. This also prevents me choking.</p>
Eating and taking nutrition	<p>I use small cutlery. Can't use standard as its handle is too long and digs into the arm which is painful and uncomfortable and can't grip the handle properly. Smaller cutlery is easier to use, you hold it at the neck (of the folk etc.)</p> <p>I am unable to cut meat therefore those that had been prepared by others were already cut up for me.</p> <p>I have microwave meals selecting ones that do not require cutting (i.e. macaroni cheese) as this reduces the risk of choking. Also it was a vegetarian microwave meal as I have huge anxiety about the way meat is cooked.</p> <p>I avoid anything with bones or chunks in as it makes me feel sick and anxious. If food is not cut up I won't eat it.</p> <p>Tins were left opened for me by others and left in the fridge, as I am unable to use tin openers.</p>

	<p>I used a small travel kettle as that is all I can lift which I still find difficult and I am concerned that I will scald myself. I use small cups which I cannot by the handle but I my finger tips to pick up.</p> <p>Thursday, I only had one meal this happens at least twice per week as I don't feel I want to eat, due to being in pain and when I take co-codamol to ease the pain I don't feel like eating.</p> <p>I get anxious when I eat especially when I am alone which is most days. I feel rushed on your own (why?). I feel very tired after I eaten (due to the effort and anxiety).</p> <p>I did not eat out as I would never eat out alone, it makes me so anxious and I feel people are watching me.</p>
Managing therapy/monitoring health condition	<p>I am currently awaiting an appointment to see a specialist regarding treatment for my carpal tunnel syndrome. I feel extremely anxious about this and will not attend any appointments alone. I will not be able to get myself there or be able to understand what I am being told as I find it so difficult to process and understand information.</p>
Medication	<p>I use a dosette box and my daughter arranges my tablets in the dosette box for me, as they all look the same and it confuses me. If she did not do this there is a danger I'd guess, taking the wrong tablet and the wrong dosage. I leave a note for myself on the side table (everyday), as if I did not I would forget to take my medication in the afternoon. If I didn't have the support and prompt my health would deteriorate – chest infections, pain increases, depression.</p> <p>I have forgotten to take medication in the past (what happened as a result).</p> <p>I worry all the time that I'll forget my medication, this makes me worried and anxious, gets me down, low mood which stops me doing things like leaving the house.</p>
Washing and bathing	<p>I use grab rails and a seated shower for safety to prevent me slipping over.</p> <p>I will only go into the shower when someone else is present in in my home in case I slip or fall. In the past I have fallen in the shower, banged the back of my head and I was taken to hospital. As a result, I am very fearful anxious, worried and nervous when showering.</p> <p>I cannot reach my back, wash my hair or shower properly. I would like to/need to shower every day, but can only do it every other day as I require someone to be there – my daughter comes every other day. Without physical help I cannot manage my personal care (showering) to a reasonable and acceptable standard.</p> <p>I am unable to use aids such as along handled sponge as I can't grip it and I cannot use my right shoulder. It is too painful in my right arm shoulder and my neck for me to do it alone, it is very frustrating and it is very tiring for me. It takes more than twice as long for me to wash and shower as a non-disabled person.</p> <p>It takes 45 mins to get washed with help. Without help I won't get washed.</p>
Going to the toilet Managing toilet needs and continence	<p>I don't have a grab rail in the toilet, so I use the sink and radiator to help me get on and off the toilet. I have to use a disabled toilet if I go out as I require the grab rails to support me to get on and off the toilet.</p> <p>I have constant back pain and when it is really painful I cannot always make it to the toilet in time, resulting in me having to change my clothing, this will happen throughout the day and on average two days per week. This makes me avoid going out as I feel embarrassed and anxious. I will only go out with my daughter or your friend.</p>

Dressing/undressing	<p>I avoid any clothing that has button or zips and laces. I wear slip on shoes, elasticated trousers and skirts. Baggy trousers. I don't wear a bra unless my daughter is there to put one on me as even front facing bras are a struggle.</p> <p>It is always real struggle and painful to put my socks and shoes on. I am unable to use a shoe horn. Putting on any clothing is a real effort, I have to sit on the bed when dressing and take breaks, it's always painful and very tiring and I will stay in my pyjamas because of this, it makes me anxious and have a low mood. I need a break after getting dressed as it's so tiring for me and I feel exhausted. Unless I am prompted or encouraged I wouldn't get dressed.</p> <p>I cannot go out unless someone puts my socks and shoes on for me as it's too painful for me to bend down and therefore I am unable to do it properly. I can't zip boots up or pull them on, therefore cannot dress appropriately without physical help for all weather conditions. (What about coats?? How do you manage them?)</p> <p>Its takes half an hour to get dressed with help when I am having a very painful day which is at least twice per week. I get very anxious and worried that you will damage my back more and be in even more pain, as this can suddenly happen any time (approx. twice per week) and totally disables me. I then have to take more pain killers and it takes 24 hours to recover.</p>
Communicating verbally	<p>Sometimes it takes me time to understand what people are telling me and I need them to repeat things. I don't always understand, sometimes it doesn't make sense, or I am unable to take information in, I don't know what to say and I may miss important information, it makes me very anxious and worried. I feel embarrassed to ask people to repeat things and will walk away with people thinking I have understood, but I haven't.</p> <p>I forget what has been said, miss instructions and information.</p> <p>I don't like communicating with people who I don't know which puts me off going out, going to places and accessing services. I avoid going out and I feel isolated and low. If my daughter or friend are with me they will answer for me and I won't go out alone. I avoid going out on a daily basis.</p>
Reading and understanding signs and symbols	<p>I wear reading glasses & daily glasses. I have been wearing glasses over 10 years. I get bad headaches and dry eyes.</p> <p>I ask my daughter or friend to check my post especially if it is letter I am not expecting as I will not understand and miss something really important.</p> <p>My daughter or friend checks all of my bills to make sure I pay the right amount.</p> <p>I cannot understand my post without help and it takes me twice as long to read it as a non-disabled person. Receiving post makes me very anxious and nervous as I don't want to miss anything important.</p>
Meeting people engaging with others face to face	<p>I do not like mixing with people, I feel embarrassed and anxious, I try to hide and I feel vulnerable. I can't talk to others so I leave it to someone else and I avoid those situations and would rather not go, even if its family (in case there is someone new), as it causes me stress and anxiety, leaves me feeling low. Someone has to be with me all of the time if I am out, I cannot be alone. The anxiety and stress of going out or social situation makes me distressed, down and tired.</p>
Budgeting decisions	<p>I am not confident to shop on my own, someone has to check the change for me to ensure it is correct.</p> <p>I won't buy anything without anyone being there as I get confused pretty quick. (Why is that? What cause it? Have you got examples you can add?)</p> <p>If you didn't have the help in the shop what would happen? My daughter or friend check all of my bills for me and confirm the amounts that need to be paid. They pay it for me using my account. If I didn't have this support I would pay the wrong amount</p>

	<p>and could end up in financial difficulty. An example when I been sent a bill which gave an over estimated cost that I was paying. I continued to pay and was paying too much, if this hadn't been checked I would still be paying it now.</p> <p>I am unable to do this regularly or reliably. Left on my own to do this would confuse me and bills wouldn't get paid or would be overpaid.</p>
Planning and following journeys	<p>I will not go out alone and never go out alone because I feel very anxious, stressed and embarrassed by my disability. I feel people are staring at me. This makes me feel anxious, low, down, depressed and tired. I can't face it or anyone on my own. I won't mix with people or talk to people that I don't know. I will only go out with family or friends. I will only go out in the car. I can't walk far due to breathlessness and back pain.</p> <p>I'd get lost and wouldn't know where I was going which has happened to me in the past.</p> <p>I need encouragement and prompting to leave the house. I get so anxious and nervous when I am out, I need people to reassure me and keep me calm, but also to take me home if I don't feel comfortable to continue.</p> <p>I won't go to busy or large places such as large shopping centres for fear of getting lost and as I cannot walk far.</p> <p>I can't plan a journey or follow a route even with help. I wouldn't speak to someone to ask for help or directions. I would have a panic attack if someone approached, I would feel frightened.</p> <p>The last time I went out alone was years ago, I go totally lost, I couldn't use the phone, my daughter had to leave work to come and get me and take me home.</p> <p>I don't drive anymore, I am not confident, can't see properly and panic.</p>
Moving around	<p>I struggle to walk around the house every day.</p> <p>I have used a walking stick for the last 3 years, but even struggle to use that and I'm not using it at the moment as my wrist is too weak to grip (carpal tunnel & pins and needles) and take the weight. I cannot stand up straight.</p> <p>I cannot walk unaided even within the home, I lean on furniture, walls and use grab rails. I cannot walk 20 meters reliably, repeatedly or safely as I am in constant pain which gets worse as I walk. I am breathless and in severe discomfort. Getting from my front door to my car (estimates this is less than 10 meters), takes approx. 4 minutes, I am breathless and in severe discomfort the whole time and take rest breaks (how many?). I would not be able to repeat this for at least half an hour.</p> <p>If I walk around the house you get cramps (where).</p> <p>I am at risk of losing my balance and falling. If I do not have something or a person to lean on I will lose my balance and fall every time. If I do fall it takes 24 hours to recover and makes me even more anxious.</p> <p>I get dizzy when I am worried and distressed and when in pain.</p>

Section B

Case Study 4 - Hearing impaired

ACTIVITY	EFFECT ON ME
Cooking/preparing food	<p>I suffer from weakness right from my wrist to my shoulder and my grip is not good, therefore I cannot grip or use sharp knives or peelers. I cannot chop hard/raw vegetables due to being unable to grip and hold the sharp knife, to do so would cause great risk of me cutting myself. I am also unable to grip or lift sauce pans, my wrists are too weak and my shoulders ache. For example, in the past when tipping the water out of the saucepan my hand shook, the lid came away and the boiling water splashed on me and burnt me. I can't open tins as I get a sharp pain in my wrist. My children or my partner do all of the chopping, tin opening, lifting sauce pans etc. On the occasion that I chop soft substances with a butter knife, I will be seated to do this. I also use an electric blender to mash if required and someone is always present.</p> <p>I can't feel sensation in my thumbs, so I can't open packets that are sealed tightly, so I will use my teeth, which is not good for my teeth!</p> <p>I am also extremely forgetful and easily distracted. I have left things on the hob to boil over or burn. If I answer the door or talk to someone it distracts me, then boils over or burns. I cannot use a timer as I won't hear it. I can't hear running water and have forgotten that the tap is running, the sink could over flow and I could then slip.</p> <p>I cannot put food in or take out of an oven, for example a chicken would be too heavy due to the pain in my shoulder and wrist.</p>
Eating and taking nutrition	<p>It always takes me longer, twice as long than everyone else to eat a meal, I always finish last. I require my food to be cut up into small pieces, as I have problems swallowing as I feel like food gets in my throat. If meats are over cooked they are too hard to cut or swallow. My arms hurt when cutting so I will only go so far then give up on anything hard (such as tough meat), or try to avoid it, sticking only to soft such as cooked vegetables.</p> <p>On an average of two to three times per week I do not feel like eating, due to my medication (co-codamol).</p> <p>Sometimes I will start a meal but then won't want it and can't finish it, I'm not sure if it's due to stress, medication or fatigue, but this happens at least 3 times per week.</p> <p>I am always anxious by the thought of meal times and about eating. If I'm really hungry I'll overeat then panic, I have to ensure I eat slow and have smaller pieces. If I rush eating I become breathless, anxious and panic.</p>
Managing therapy/monitoring health condition	
Medication	<p>I keep my thyroid tablets on my bedside cabinet otherwise, I would forget to take them, which has happened on occasion.</p> <p>My partner always has to apply the cream on my back for my eczema, as I am unable to do this due to weakness and pain in my shoulders and arms I am unable to reach.</p>

Washing and bathing	<p>I have a low step shower and a rubber mat to limit the risk of slipping due to my balance issues relating to my deafness and also my vertigo. In my previous shower without the lower step I fell and knocked my arm.</p> <p>I can't wash my back to a reasonable standard as I cannot reach it. It is too painful, I to have let water run down my back. It takes me at least twice as long to shower as a non-disabled person.</p> <p>Someone always has to be the house (usually my partner), when I go in the shower in case I fall. I have to bring my phone in with me as I would need to text to alert my partner as he is also deaf, but also I cannot alert a hearing person vocally.</p> <p>On a bad day I prefer a bath to ease the pain all over my body, however as my shoulders and arms are weak I cannot lift my own body weight in and out of the bath myself without difficulty. I have a bad day at least 3 times a week, as I over exert myself which causes my body to be very painful and achy.</p> <p>I am anxious when getting in and out if the bath or shower due to my concern about falling and hurting myself.</p> <p>After showering I am worn out, it then takes me longer to do tasks and I am in pain.</p>
Going to the toilet Managing toilet needs and continence	<p>At home I use the sink to steady myself when lowering myself on to the toilet due to my balance problems. I'll also use the sink to pull myself up off the toilet otherwise I would not be able to. I struggle to get myself up because my legs are weak and painful. Outside the home I use the disabled toilet, as I use the grab rail to steady myself when lowering and pulling myself up. I find the disabled toilet better to use than the one at home as it is higher and therefore less pressure on my legs when sitting and standing. It takes me at least 1.5 times longer than that of someone without my condition to go to the toilet.</p> <p>It is even more difficult when I have increased back pain which is more than 50% of the time.</p>
Dressing/undressing	<p>Due to the lack of sensation in my fingers I avoid buttons as they are too difficult for me to do. I cannot use a zip if it is at the back. I have great difficulty fastening my bra, it is extremely painful, but I have to grin and bear it.</p> <p>If it is a fitted garment I cannot put it on by myself, my partner has to help me put it on and take it off. I haven't got the strength or ability in my arms to manage it as my shoulders are weak. I cannot pull boots or trainers on, nor can I lace them up my partner has to do this for me. I choose shoes that I can slide my foot into, but if it's a boot to slide my foot into, I cannot take it off myself.</p> <p>When dressing I always have to sit on the bed due to my balance and dizziness issues. It takes me at least 1.5 times longer to dress than someone without my condition and I become worn out each time and on a bad day also breathless. It is even more difficult and tiring in winter due to type and amount of clothing.</p>
Communicating verbally	<p>As I am profoundly deaf I find it very difficult communicating in the hearing world.</p> <p>I have a flash doorbell, but I need to be looking at it to see it flash and know someone is at the door, so I can and do miss people.</p> <p>I have a glide app on my phone, but that can only be used between deaf people. I also use facetime so I can sign with people.</p> <p>I have had experience of people coming to my door, realising I am deaf and then walking away.</p> <p>In Asda I went to order one of the pick your own toppings pizza and the person shouted over to the staff member "Oi it's a deaf person", it felt so embarrassing.</p> <p>On another occasion in the past, I got on the correct train. There was an announcement made on the train that I obviously couldn't hear. A few people got off, I never gave it any thought and it went somewhere completely different! I was crying and in</p>

	<p>a panic, I didn't know where it was going. I had to wait to get the next train back, it was really awful. It has put me off using the train and I have to have someone with me.</p> <p>I am unable to lip read very well at all and therefore I require an interpreter. I miss information. I was once waiting at a doctor's surgery and wondered why I hadn't been called. I had waited an hour, so I went to the reception and they said my appointment was finished that I had to rebook!</p> <p>I cannot always use a friend or family to interpret on my behalf as they impose their own views, change or adapt what's been said and cut out information, so my voice is gone. It is difficult to book interpreters though.</p> <p>When I use pen and paper to communicate people cannot understand my writing or what I have written and I feel intimidated. I have low level English and spelling. When reading I can only pick out some words that I know. I don't understand it all, I try to make sense of it but I miss relevant words.</p> <p>Every letter I get someone has to help me with – school reports for my daughter, my medical reports etc.</p> <p>I only have a few hearing friends and they are translators.</p> <p>I experience situations where people are aggressive towards me. For example, a man came past me from behind, he appeared to be shouting at me in an aggressive manner asking why I didn't move, of course I could not hear him, nor did he know that. I have this uncertainty every day which is stressful and causes me anxiety.</p> <p>I cannot hear car horns, fire engines, police cars etc. and this frightens me and puts me at risk.</p>
Reading and understanding signs and symbols	<p>I don't understand menus. I can't read directions or understand a map. As stated previously I have low level reading age and I miss important information, so someone always has to go through my mail and important documents with me and translate them to me.</p> <p>Sometimes the words are blurry and I can't see them clearly.</p> <p>I find it very difficult to connect with the hearing world which is so stressful and can make me very anxious on a daily basis.</p> <p>I have problems with my left eye, the muscles don't move, therefore I have to physically I move my head to see which is really tiring for me.</p>
Meeting people engaging with others face to face	<p>Meeting new people is difficult, so can mixing with people I know, depending on how many there are. I find people can become aggressive and are not aware of deafness as described in a number of examples already given above, Asda, the doctor's surgery, the aggressive passer, which impacts on my daily life. This makes me nervous and anxious. I have fear that something might happen, how would a hearing person know? How would they understand? I don't feel safe.</p> <p>If I turn to look at someone and the might misinterpret this, lose patience with me or push me out of the way, which I have experienced.</p> <p>I wouldn't mix with a group of people without an interpreter. I would become stiff, wouldn't feel safe and would feel on edge. It would take me a very long time to mix, I just avoid it.</p>
Budgeting decisions	<p>I always use a bank card, I do not feel safe to carry cash.</p>
Planning and following journeys	<p>I have Sat Nav which I always use.</p> <p>I have a special app on my phone that says where I am and where I need to be, so I follow that. I will only drive locally to places that I know.</p>

	<p>I panic easily and worry about risk of accidents. I would struggle with an unexpected change to a journey, as I clearly explained already in regard to the train incident. I will not do a train journey or bus journey alone ever, for fear of a similar situation happening. I will not travel at night or in the rush hour. I avoid crowded places. I have to be with my partner and hold his hand to reassure me or I will become anxious and panic.</p> <p>I don't drive very much or very far – max half an hour. I get very tired very quickly and can't hold the steering wheel for any length of time as my shoulders and arms ache. I have an automatic car due to my arm issues, when driving a manual car previously my arm locked when putting it into gear. Also my medication can make me feel tired. If I feel drowsy after taking it I won't drive.</p> <p>I cannot hear car horns, fire engines, police cars etc. and this frightens me and puts me at risk.</p> <p>I experience situations where people are aggressive towards me. For example, a man came past me from behind, he appeared to be shouting at me in an aggressive manner asking why I didn't move, of course I could not hear him, nor did he know that. I have this uncertainty every day which is stressful and causes anxiety.</p>
Moving around	<p>Over 50 % of the time (4 times per week), I require a stick and/or rest breaks when walking this short distance. I can become breathless, sometimes I even give up and my partner has to come and give me a lift. This wipes me out for the rest of the day and I cannot do any tasks for the remainder of the day. I cannot walk this distance reliably, repeatedly to a reasonable standard in a reasonable amount of time. I have pain in my legs and back and when I am suffering the dizziness from the vertigo I have to sit down.</p> <p>If there are steps I have to use a hand rail due to risk of falling. Due to my eye condition, if the colour of the steps contrast is not so good and I don't have a hand rail I could over step, or miss the step and tumble. If there isn't a hand rail available I have to rely on my partner.</p> <p>Due to my balance issues and eye condition I have fallen due to obstacles on pathways or uneven paving slabs.</p>

Section B

Case Study 5 - Lower limb affected

ACTIVITY	EFFECT ON ME
Cooking/preparing food	<p>As I am unable to prepare or cook a simple meal for myself, I have readymade meals during week days which I cook in the microwave, or a salad or pasta box. At weekends I eat out.</p> <p>I am unable to prepare or cook a meal by myself, it would take me a very long time – a good few hours.</p> <p>As I have small hands and missing fingers I have difficulty holding objects, so a Sharpe object such as a knife or peeler is likely to slip and cut me and carry hot saucepans is not safe for me as I would scald and burn myself.</p>
Eating and taking nutrition	None.
Managing therapy/monitoring health condition	I sometimes need help from another person, especially if it's physical treatment, I would need someone to help me.
Medication	I would need somebody to open screw top bottles for medication and also to apply creams to certain parts of my body that I can't reach.
Washing and bathing	<p>I use an aid every time to wash myself.</p> <p>I bath every other day, each time I use a back washer aid. I use a dining chair to get out of the bath safely.</p> <p>Due to my short arms it takes me twice as long to wash my hair as I have to do one side first and then the other.</p>
Going to the toilet Managing toilet needs and continence	Every day I use a bottom wiper. I use a standard toilet, I need a dining chair when at home, or use my wheelchair when I'm out to lever myself onto the toilet. Without doing this I would need help from someone else.
Dressing/undressing	To dress myself I sit on the floor. When I need to pull up my underwear and trousers I lean on the bed so I don't lose my balance. I never wear shoes as my feet are turned up and there isn't any suitable foot wear available for me.
Communicating verbally	<p>I always use a hearing aid and without it I cannot hear at all. On some phones I use the loud speaker if the person is quiet.</p> <p>I find it difficult to understand some accents, when this happens I get someone to help and explain.</p>
Reading and understanding signs and symbols	None.
Meeting people engaging with others face to face	On occasion I feel people aren't sure how to approach me and I sometimes need help to mix with other people.

Budgeting decisions	I don't need help on a day to day basis, however, for something such as booking a holiday or buying furniture (3 or 4 times per year), my brother helps me.
Planning and following journeys	No issues.
Moving around	<p>When I am outside I always use my motorised wheelchair. I cannot walk outside alone because the outside surfaces are hard and uncomfortable for me to walk on – I am unable to wear shoes as my feet are turned up. So there isn't any suitable footwear available.</p> <p>Even to walk less than 20 meters require me to take rest breaks, I get breathless and it's painful on my legs and feet when walking on hard surfaces.</p> <p>I am also at risk of falling due to pain and balance. It would take me at least half an hour before I could start to walk again. I try not to walk if I don't have to as it makes life difficult for me.</p> <p>When in doors I can walk around the house on carpet. I use my electric chair in the kitchen because of the hard wooden floor and to enable me to use the microwave and kettle.</p>

Section B

Case Study 6 – Upper limb, ear and eyesight issues

ACTIVITY	EFFECT ON ME
Cooking/preparing food	<p>Cooking: my condition doesn't allow me to cook, or prepare simple foods. Appliances like kettles, ovens, hobs, sharp knives and microwaves are particularly dangerous for me to use because of risks of spills and scalding due to upper limb impairments. I require assistance for all meals. I use only a fork to eat, I cannot use a knife. I cannot cook, use a microwave, open tins, packets, and oven doors safely. I do not have the strength or coordination in my hands to lift pans or saucepans and I would burn and scald myself if I did. I cannot lift plates pans trays etc as my arms are too short to reach around them to lift them up or hold them safely, even if the food is cold. All food has to be cut for me. If food is not cut up I can't eat it. Fearful of cutting myself on sharp knives, poor dexterity and not enough pressure to use a blunter knife means I cannot use a knife.</p> <p>I cannot open tins or packets, jars or other containers such as Tupperware. I am unable to use a microwave safely - in the past I suffered a burn and dropped a plate of food which I could not clean up, and I have not tried since. I cannot lift hot plates because of the risks of burns.</p> <p>Making snacks I find difficult due to issues with retrieving items from the fridge, it is hard for me to reach and grip, my left hand is particularly weak. I cannot make sandwiches as I cannot use a knife. Poor dexterity / hand strength is why I have been assessed by the local authority as needing an assistant to assist me with making snacks and meals. In fact I don't actually have hands at all, just five fingers spread across two arms which are extremely short (each in total including arms and fingers is just 8 inches).</p> <p>I am unable to cut bread or butter sliced bread, as even were I able to hold a knife and cut bread – which I can't, buttering back and forth would, be impossible to manage physically. In addition, bending over repeatedly causes back pain. I would have to pause, straighten up and start again.</p> <p>All tasks that are below or above waist height cause my back and shoulders considerable pain to bend or stretch over to manage. I am unable to lift a kettle to make a cup of tea as don't have the strength. I have previously scalded myself with hot water trying to do this and I am unable to hold the boiling kettle away from my body due to lack of arm length. It would be in direct contact with my chest. To stand in the kitchen at the hob is dangerous as explained above, and avoided. I do not cook or prepare any meals for myself.</p> <p>The local authority have recently reviewed my care plan with an up to date review in October (I think) 2017. I have had the same care plan for many years; and it enables me to maximize my independence whilst balancing the risk of harm to my physical, social, emotional wellbeing.</p>
Eating and taking nutrition	<p>I need to have assistance to be able to cut up food. Cutting tough foods, peeling food, I can't manage safely as I can't use a knife properly. Poor dexterity and strength make this impossible. I eat with a fork at all times. I even eat toast and potato crisps with a fork -</p>

	<p>I cannot raise my hand to my mouth. I struggle to use a spoon as in order to reach my mouth it has to be turned upside down, causing food to fall off. Cutting food is impossible. If I go out to dinner, I need food to be cut up for me.</p> <p>I drink through a straw as it causes me pain to lift a glass and would take longer than a reasonable time to struggle to lift and put a cup/mug down on a surface. I am also at risk of burning myself should I try to hold a cup, as it is against my body.</p>
Managing therapy/monitoring health condition	<p>I need supervision to manage medication or monitor a health condition.</p> <p>Daily regime - unable to open packaging and need PA assistance.</p> <p>I require occasional heat treatment and physiotherapy when pain peaks for example in the winter or after I have used my fingers and arms for a task for more than a short time.</p> <p>I have musculo-skeletal manipulation through firm massage on a regular basis in an attempt to reduce back and shoulder pain. I require regular weekly massage to manage my chronic condition. Physiotherapist manipulates my neck and hand joints when acute pain arises. I also have damage to my knees which requires treatment by a physiotherapist, as a result of using my knees in inappropriate ways, due to having no arms.</p> <p>Additionally, as I cannot wear gloves, I require a wheat pack or a hot gel pack to put on my hands to relieve pain, which someone else microwaves and applies for me.</p> <p>If I go swimming or exercise I can't get my wet costume/clothes off without help. My GP has recommended exercise to help manage my weight and encourage mobility, but in order to do this I have to work with a sports therapist as I am unable to use any equipment or do exercise without assistance</p>
Medication	<p>I need someone to give me tablets on a daily basis, as I am unable to take them out of their packaging.</p> <p>I take antacids. My doctor told me I was obese two years ago, and although I am trying to lose weight, it is still the case. This causes acid reflux as when I bend forwards pressure on my stomach when performing activities as I cannot reach anything when upright, has exerted stress on the valve over the years has meant that acid leaks out, and caused damage to my stomach lining and oesophagus hence antacids are required. Antacids are in foil sheets/containers which I can't open with my hands. When I tried to use my teeth, I cut my tongue, and my mouth in the corner, on the sharp foil packaging.</p> <p>I take glucosamine for joint pain as anecdotally this provides relief for painful joints. I am unable to remove the plastic seal initially, and I unable open the bottle daily. Someone puts the tablet on a surface for me to suck in.</p> <p>Creams or sprays are applied by others as I am unable to reach and apply to an acceptable standard. For example I currently have athletes foot requiring cream application daily.</p>
Washing and bathing	<p>I cannot wash and bathe at all and need another person to wash my entire body, including hair. Need assistance to shower. Without physical help I cannot manage my personal care (showering) to a reasonable and acceptable standard. I wouldn't be able to do so to an ACCEPTABLE STANDARD and safely.</p> <p>I can't reach to wash all areas of my body. I require help to dry myself too as unable to manage this. In the past I have fallen in the shower, banged the back of my head and for an instant I passed out and I laid motionless until I came around fully and was able to get up.</p> <p>I am unable to wash and scrub body everywhere. I cannot wash my hair. Aids such as along handled sponge can't reach everywhere, and I cannot raise my hands to reach my head. It is very frustrating and it is very tiring for me.</p>

	<p>Drying: after I have showered , I must sit on the bed totally motionless for 10 minutes to stop sweating (as it is physically demanding) to fully dry off, due to my body having very poor temperature control.</p> <p>I use an electric toothbrush as I lack sufficient dexterity to use a regular toothbrush but someone has to put the toothpaste on the brush for me.</p> <p>Teeth: maintaining and manage dental care difficult, can't reach all teeth. I have bad teeth as a result which are painful. I have to go to the dentist every two months for hygiene care.</p> <p>Foot care. I am unable to cut my own toenails or care for my feet.</p> <p>It takes more than twice as long for me to wash and shower as a non-disabled person. It takes 75 mins to get washed with help. Without help I won't get washed.</p>
<p>Going to the toilet Managing toilet needs and continence</p>	<p>I need assistance to be able to manage my toilet needs. Unable to dress and undress before and after. This takes longer than a person without a disability so I am unable to manage this in reasonable time. When out I need assistance with fastenings on trousers, tucking in and adjusting garments as I am unable to manage this to an acceptable standard.</p> <p>I am frequently dehydrated as I limit my fluid intake to minimize toilet needs when out. This causes constipation, bad breath, and headaches. This stops me going out.</p>
<p>Dressing/undressing</p>	<p>I cannot dress or undress without help. Assistance is needed with every item of clothing. I cannot do this myself to an acceptable standard and in reasonable time. Need full assistance with dressing.</p> <p>I always need help to put on and take off outdoor clothing, unable to put arms in coat and zip up my coat, and am frequently cold when out. I cannot wear gloves so am often in pain and unable to move my arms in outdoor jackets and as a result I am unable to do anything with my fingers if I am wearing a coat. Can't manage to an acceptable standard and safely e.g. risk of harm from catching cold, getting wet and getting ill in poor weather.</p> <p>I am unable to lift jumpers over my head, I have my clothes specially adapted for me, especially those on my upper half i.e. my coat has been adapted. I am not able to do up or undo and buttons, belts or fastenings, including my coat. I am unable to do up shoes or trainer laces. I am unable to use a shoe horn. I avoid any clothing that has button or zips and laces.</p> <p>Putting on any clothing is a real effort, I have to sit on the bed when dressing and take breaks, it's always painful and very tiring and I often stay in my pyjamas because of this. I need a break after getting dressed as it's so tiring for me and I feel exhausted.</p> <p>As a result of poor temperature control, the slightest activity causes me to sweat significantly, making it impossible for me to adjust, put on or take off clothing. I can't zip boots up or pull them on, therefore cannot dress appropriately without physical help for all weather conditions. I get very anxious and worried that I will damage my back more.</p>
<p>Communicating verbally</p>	
<p>Reading and understanding signs and symbols</p>	<p>I need to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. For work, I have a large screen computer 27" and use the built-in text-to-speech technology. A standard mouse causes repetitive pain in arms, shoulder and neck. Limited typing is possible.</p> <p>I am unable to open post and cannot hold a book to read it. I have had laser eye surgery carried out on the NHS as I am unable to put glasses on and off easily or clean them.</p>

Going out	<p>There is risk of falls, which also adds to anxiety. I cannot use public transport. I use taxis rather than public transport. I have a blue badge as I am unable to use parking machines or apps on a mobile phone in order to pay for parking. I am unable to drive if I have eaten or drunk anything as the forward position required for me to reach the steering wheel, causes acid reflux, discomfort to my stomach and nausea.</p> <p>I am unable to go out unless someone is able to lock my front door as I have damaged several teeth attempting to do it alone as my fingers won't allow me to turn keys.</p>
Moving around	<p>Walking is inhibited by balance issues and fear of falls, the consequences of which can be extremely serious because of my upper limb impairments. I recently tripped on a pavement and was knocked unconscious as I was unable to limit the damage caused by falling. I also had stitches as a result and damage to my knee which required physiotherapy and lasted several months.</p>
Planning and following journeys	<p>I avoid public transport because I worry about being knocked. I can't hold onto rails on public transport if no seat is available.</p> <p>I am unable to carry bags and parcels when I go out, so I require someone to go with me.</p>
Additional information	<p>When assessing this application for Personal Independence Payment, the compound effects of the impairments already described in the questionnaire have to be taken into account. My disability is not temporary, it is lifelong congenital damage caused by medication (thalidomide) taken by my mother before birth. These disabilities can never be altered or improve and is why I have received DLA and prior to that Attendance Allowance, since I was a child. My condition will worsen with age as my body and joints continue to deteriorate as a result of a lifetime of using my body (in particular legs and feet) in ways that it was never intended to be used.</p> <p>Unfortunately, the whole is greater than the sum of the parts: for instance, having severely shortened upper limbs means that there is an exaggerated risk of falling brings an enhanced risk of injury due to an inability to save oneself.</p> <p>The lack of physical activity then causes a sedentary lifestyle which in turn brings weight issues. Weight issues increases joint strain, pain. Short arms also causes stomach acid issues due to the increased need to lean forward and with a large waist this pressurizes the stomach causing acid leakage.</p> <p>The difficulty with dressing causes you to drink less so you don't need the toilet so much. This causes dehydration which cause headaches, irritability, and constipation.</p> <p>There is a wealth of medical information that shows accelerated ageing among those disabled by the morning sickness drug, thalidomide. It is estimated by the Heidelberg University School of Gerontology that thalidomidors are accelerating their ageing by at least 20 years: the authors found advanced wear and tear on joints and other musculo-skeletal damage, internal organ damage (previously undiagnosed) and mental health issues resulting from a lifetime of living with complex impairments.</p>

Section C

For people you are asking to write evidence for you

The following pages are written for medical staff, social workers, and other professionals, who might be able to tell the DWP what they need to know in order to back up your application for PIP. They detail how to write helpful evidence for you and explain how this should support and corroborate your PIP application.

Before you give the information below to the professional, providing the evidence, you need to mark which descriptor you feel you meet. It would be beneficial to consider each of those you have marked within the reliably test. If you are not sure about this element of your application, you may wish to turn to an organisation that can assist you to understand the reliably test and which descriptors explain your difficulties best within the 'reliably' parameters.

A guide to supporting your patient/client by providing robust supporting evidence

Evidence from doctors and other professionals helps the tribunal to come to the right decision more than anything else. Your evidence doesn't need to be long or typed.

Whether your patient/client is entitled to PIP is decided by the difficulties they experience and the help they need with very specific tasks. The DWP have termed these tasks, 'descriptors'. Your patient/client is approaching you to provide your professional opinion on the difficulties and degree of each of these descriptors and how impact upon different areas of their everyday life.

Your patient/client has written in detail on their application form information relating to the descriptors they feel they meet below. They have also highlighted in this letter which ones that cross reference to their application and that best meet their circumstances. Please would you look at each of those they have chosen and confirm all of those that you can in your written evidence in a letter format. For example, in the mobility descriptor, under 'getting' around, if they cannot walk even into your consulting room without discomfort, or if they are slow and it takes them twice as long as somebody else, please say that. You may wish to use the descriptor heading that is used below to help guide your letter structure. It is important that your patient/client experiences that difficulty for more than 50% of the time (using a 12 month period as an average)

If you cannot confirm the descriptor your patient has circled but can confirm another in that section, please include that. If you cannot confirm any from that section please just leave it out as your patient may have evidence from someone else who knows more about their problems with this. If you don't understand why your patient meets the descriptor they have circled, please ask them.

If your patient could do some of these things but not reliably, safely, repeatedly or only very slowly it counts as being unable to do it. For example, if they can stand and walk for 50 meters, but they can only do it a few times in a day, it may hurt them, they might sometimes fall, or it takes them twice as long as someone else, the law sees this as not being able to walk for 50 metres.

Your evidence needs to be about how their illness or disability affected them at that time, has lasted 6 months prior and is likely to last 6 months or more in the future.

It would also be helpful if your evidence confirmed any diagnosis and any treatment that they receive.

After the listing of the descriptors is some further information that may be useful when formulating your letter. It includes further explanation of the reliably test, what aids and appliances mean and how safely is interpreted by the DWP. There is additional detail on what support from another person entails as well as more detail on the 50% of the time rule.

Daily living activities and descriptors

Activity 1. Preparing food

- a. Can prepare and cook a simple meal unaided. – Score 0
- b. Needs to use an aid or appliance to be able to either prepare or cook a simple meal. - Score 2
- c. Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave. - Score 2
- d. Needs prompting to be able to either prepare or cook a simple meal. - Score 2
- e. Needs supervision or assistance to either prepare or cook a simple meal. - Score 4
- f. Cannot prepare and cook food. – Score 8

Activity 2. Taking nutrition

- a. Can take nutrition unaided. - Score 0
- b. Needs either (i) to use an aid or appliance to be able to take nutrition; or (ii) supervision to be able to take nutrition; or (iii) assistance to be able to cut up food. - Score 2
- c. Needs a therapeutic source to be able to take nutrition. - Score 2
- d. Needs prompting to be able to take nutrition. - Score 4
- e. Needs assistance to be able to manage a therapeutic source to take nutrition. - Score 6
- f. Cannot convey food and drink to their mouth and needs another person to do so. Score 10

Activity 3. Managing therapy or monitoring a health condition

- a. Either (i) does not receive medication or therapy or need to monitor a health condition; or (ii) can manage medication or therapy or monitor a health condition unaided. Score 0
- b. Needs either (i) to use an aid or appliance to be able to manage medication; or (ii) supervision, prompting or assistance to be able to manage medication or monitor a health condition. - Score 1
- c. Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. - Score 2
- d. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week. - Score 4
- e. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week. - Score 6

f. Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. - Score 8

Activity 4. Washing and bathing

- a. Can wash and bathe unaided. - Score 0
- b. Needs to use an aid or appliance to be able to wash or bathe. - Score 2
- c. Needs supervision or prompting to be able to wash or bathe. - Score 2
- d. Needs assistance to be able to wash either their hair or body below the waist. - Score 2
- e. Needs assistance to be able to get in or out of a bath or shower. - Score 3
- f. Needs assistance to be able to wash their body between the shoulders and waist. - Score 4
- g. Cannot wash and bathe at all and needs another person to wash their entire body. - Score 8

Activity 5. Managing toilet needs or incontinence

- a. Can manage toilet needs or incontinence unaided. - Score 0
- b. Needs to use an aid or appliance to be able to manage toilet needs or incontinence. - Score 2
- c. Needs supervision or prompting to be able to manage toilet needs. - Score 2
- d. Needs assistance to be able to manage toilet needs. - Score 4
- e. Needs assistance to be able to manage incontinence of either bladder or bowel. - Score 6
- f. Needs assistance to be able to manage incontinence of both bladder and bowel. - Score 8

Activity 6. Dressing and undressing

- a. Can dress and undress unaided. - Score 0
- b. Needs to use an aid or appliance to be able to dress or undress. - Score 2
- c. Needs either (i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or (ii) prompting or assistance to be able to select appropriate clothing. - Score 2
- d. Needs assistance to be able to dress or undress their lower body. - Score 2
- e. Needs assistance to be able to dress or undress their upper body. - Score 4
- f. Cannot dress or undress at all. Score 8

Activity 7. Communicating verbally

- a. Can express and understand verbal information unaided. - Score 0
- b. Needs to use an aid or appliance to be able to speak or hear. - Score 2
- c. Needs communication support to be able to express or understand complex verbal information. - Score 4
- d. Needs communication support to be able to express or understand basic verbal information. - Score 8
- e. Cannot express or understand verbal information at all even with communication support. - Score 12

Activity 8. Reading and understanding signs, symbols and words

- a. Can read and understand basic and complex written information either unaided or using spectacles or contact lenses. – Score 0
- b. Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. - Score 2
- c. Needs prompting to be able to read or understand complex written information. - Score 2
- d. Needs prompting to be able to read or understand basic written information. - Score 4
- e. Cannot read or understand signs, symbols or words at all. - Score 8

Activity 9. Engaging with other people face to face

- a. Can engage with other people unaided. - Score 0
- b. Needs prompting to be able to engage with other people. - Score 2
- c. Needs social support to be able to engage with other people. - Score 4
- d. Cannot engage with other people due to such engagement causing either (i) overwhelming psychological distress to the claimant; or (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person. - Score 8

Activity 10. Making budgeting decisions

- a. Can manage complex budgeting decisions unaided. – Score 0
- b. Needs prompting or assistance to be able to make complex budgeting decisions. - Score 2
- c. Needs prompting or assistance to be able to make simple budgeting decisions. - Score 4
- d. Cannot make any budgeting decisions at all. - Score 6

Mobility activities and descriptors

Activity 1. Planning and following journeys

- a. Can plan and follow the route of a journey unaided. - Score 0
- b. Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant. - Score 4
- c. Cannot plan the route of a journey. - Score 8
- d. Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid. - Score 10
- e. Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant. - Score 10
- f. Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. - Score 12

Activity 2. Moving around

- a. Can stand and then move more than 200 metres, either aided or unaided. - Score 0
- b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. - Score 4
- c. Can stand and then move unaided more than 20 metres but no more than 50 metres. - Score 8
- d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres. - Score 10
- e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. - Score 12
- f. Cannot, either aided or unaided, (i) stand; or (ii) move more than 1 metre

Further information

Frequency of difficulty required to qualify for each particular descriptor

Taking a view of ability over a longer period of time helps to iron out fluctuations and presents a more coherent picture of disabling effects. Therefore the descriptor choice should be based on consideration of a 12 month period.

If one descriptor in an activity applies on more than 50 per cent of the days in the period – i.e. over a 12 month period, the activity cannot be completed in the way described on more than 50 per cent of days – then that descriptor should be chosen.

Reliably, in a timely fashion, repeatedly and safely An individual must be able to complete an activity descriptor reliably, in a timely fashion, repeatedly and safely; and where indicated, using aids and appliances or with support from another person (or, for activity 10, a support dog). Otherwise they should be considered unable to complete the activity described at that level.

Reliably means to a **reasonable standard**.

In a **timely fashion** means in less than twice the time it would take for an individual without any impairment.

Repeatedly means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue – i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

Safely means in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person.

Risk and Safety When considering whether an activity can be undertaken safely it is important to consider the risk of a serious adverse event occurring. However, the risk that a serious adverse event may occur due to impairments is insufficient – there has to be evidence that if the activity was undertaken, the adverse event is likely to occur.

Aids and appliances Aids are devices that help a performance of a function, for example, walking sticks or spectacles.

Appliances are devices that provide or replace a missing function, for example artificial limbs, collecting devices (stomas) and wheelchairs.

Takes in to account aids and appliances that individuals normally use and low cost, commonly available ones which someone with their impairment might reasonably be expected to use, even if they are not normally used.

Individuals who use or could reasonably be expected to use aids to carry out an activity will generally receive a higher scoring descriptor than those who can carry out the activity unaided.

Support from other people where individuals need the support of another person or persons to carry out an activity – including where that person has to carry out the activity for them in its entirety. The criteria refer to three types of support:

Assistance is support that requires the presence and physical intervention of another person i.e. actually doing some or all of the task in question. This specifically excludes non-physical intervention such as prompting or supervision which are defined below. To apply, this only needs to be required for part of the activity.

Prompting is support provided by reminding or encouraging an individual to undertake or complete a task but not physically helping them. To apply, this only needs to be required for part of the activity.

Supervision is a need for the continuous presence of another person to avoid a serious adverse event from occurring to the individual. There must be evidence that any risk would be likely to occur in the absence of such supervision. To apply, this must be required for the full duration of the activity.

Unaided 'Unaided' means without either the use of aids or appliances or assistance/prompting/supervision from another person.

Section D

PERSONAL INDEPENDENCE PAYMENT

A guide to making a claim