

The Thalidomide Trust

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>

	<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.</p>
<p>Managing therapy/monitoring health condition</p>	<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:</p> <p>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.</p> <p>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>
<p>Medication</p>	
<p>Washing and bathing</p>	<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>
<p>Going to the toilet Managing toilet needs and continence</p>	<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>
<p>Dressing/undressing</p>	<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	I cannot follow the route of a familiar or unfamiliar journey without another person, an assistance dog or an orientation aid.

	<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> <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.</p>
Moving around	<p>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.</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. 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.</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 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.</p>