

The Thalidomide Trust

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 - 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 long 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>

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. 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 thalidomiders are accelerating their ageing by at</p>

	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.
--	---