

## The Thalidomide Trust

### 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 fork 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 &amp; 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),</p>

	<p>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.  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?)  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 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.  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.  I'd get lost and wouldn't know where I was going which has happened to me in the past.  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.  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.  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.  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.  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.  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 &amp; pins and needles) and take the weight. I cannot stand up straight.  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.  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>
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