

## The Thalidomide Trust

ACTIVITY	EFFECT ON ME
<p>Cooking Preparing food</p>	<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. <b>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.</b></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>
<p>Eating and taking nutrition</p>	<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. 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><b>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.</b> In my previous shower without the lower step I fell and knocked my arm. 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><b>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.</b></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 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. It is even more difficult when I have increased back pain which is more than 50% of the time.</p>

<p>Dressing/undressing</p>	<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>
<p>Communicating verbally</p>	<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. 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 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><b>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 manor 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.</b></p> <p><b>I cannot hear car horns, fire engines, police cars etc. and this frightens me and puts me at risk.</b></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><b>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, Adsa, the doctor's surgery, the aggressive passer, which impact 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.</b></p> <p><b>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.</b></p> <p><b>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.</b></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><b>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 regards 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.</b></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><b>I cannot hear car horns, fire engines, police cars etc. and this frightens me and puts me at risk.</b></p> <p><b>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 manor 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.</b></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>