

# Securing our Future

The disability and health costs of  
UK thalidomide – affected people



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National Advisory Council to the  
Thalidomide Trust

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# 1. Executive Summary

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The unique group of 430 or so UK-born thalidomiders who still reside in the UK, have disabilities and deformities caused by their mothers taking thalidomide tablets between 1958 and 1962, which had been approved by an agency of the UK Government and released via the NHS on to the market in 1958 by Distillers Biochemicals (DCBL), as a ‘completely safe’ sedative and cure for morning sickness.

Thalidomiders are now experiencing premature, excessive, painful and debilitating wear and tear on their bodies after 50 years of having to use them in extraordinary ways to compensate for missing, shortened or malformed limbs and organs – damage which has been compounded by their inability to invest in their special needs through lack of funds.

The Securing our Future (SOF) study, initiated and managed by thalidomiders, collected data on and investigated the financial costs of living with disabilities caused by thalidomide, over and above the general costs of living.

Over a 2-year period (2010-2012) 80 of the 430 or so UK-born thalidomiders recorded their costs of coping with their thalidomide disability.

The headline finding is that an average thalidomider spends £40,594 per annum on needs directly attributable to thalidomide disabilities, and that for many, there is still a gap in their ability to invest in their real needs.

This gap is worsening as thalidomiders are losing their ability to carry on in paid employment. 15 (19%) of the 80 participants in the Securing Our Future study reported a new loss or reduction of their earned income during the 2 years of the study, averaging a loss or reduction of £20,573 per person per annum. Many others reported that they either stopped before the study period or will have to do so in the near future.

The quantitative financial information in this SOF report is intended to complement the qualitative-based research into thalidomiders’ “well-being and quality of life” being conducted during the same period by Firefly for the Department of Health (Firefly have published 2 reports and the final report is due in summer 2013).

This final SOF report, compiled by thalidomiders, details the evidence and reasons for the exceptionally high costs of having a thalidomide disability from birth, compounded by 50 years of compensating for missing or shortened limbs, using their bodies to stretch and strain in extraordinary ways that has caused further damage and pain.

The highest annualised levels of spend are on independent mobility (adapted cars, wheelchairs, their maintenance and saving for replacements), running thalidomide homes and buying adaptations and specialised equipment to maintain their independence.

Car adaptations for a thalidomider with short or no arms can cost up to £35,000 (on top of the basic cost of the car), and a van adapted for a four limb deficient to drive from a wheelchair can cost up to £65,000.

A motorised wheelchair with joystick steering costs up to £8,000 and may last only two or three years with constant use. Maintenance and insurance costs are up to £1,000 per annum.

Private medical treatment to cover for services unavailable from or limited by the NHS is costing £4,700 per annum, and there are high recorded levels of expenditure on paid assistance, such as personal carers, over and beyond what is funded by Direct Payments, Independent Living Fund and other Local Authority arrangements.

As thalidomiders' health deteriorates their partners/spouses are becoming ever more restricted in their income-generating capability as they reduce or stop working to provide care and assistance at home.

All these extra costs of thalidomide disability are increasing at a time that thalidomiders themselves are becoming more restricted in their own ability to earn an income.

Evidence is showing that the financial cost will increase in line with deteriorating state of health, as late-onset symptoms of bodily wear-and-tear and neuropathy continue to bite into their ability to cope.

In 2012 a report by Heidelberg University, Germany, into the health of 980 German thalidomiders shows a clear increase in secondary symptoms that have developed on top of the original thalidomide damage. This deterioration in their health has accelerated in the last 2 to 3 years.

Thalidomide-affected people who were born in the UK, have recourse to an annual allocation from the Thalidomide Trust based on an early and inadequate settlement with Distillers Biochemicals (now incorporated into Diageo Plc). From this fund nowadays, the average payment to a thalidomider is less than the annual average wage, but many rely almost entirely on this for their (and perhaps their family's) general living costs. It has never been enough to allow them to invest properly in their special needs. This has resulted in them damaging their bodies further by straining themselves in inappropriate and risky ways. It also means that a significant proportion are now unable to work for a paid income, with many more coming out of paid employment in the next few years.

The government health grant has allowed them to begin to make inroads in the investments needed, but even this has not been enough to avoid having to make dangerous choices between capital spend on adaptations and better housing options, and their increasing need for regular-assured spend on paid assistance and the other cumulative everyday needs that add up.

Never before have the true financial costs of thalidomide been calculated – costs that thalidomiders live with every day due to the damage caused 50 years ago. The evidence from this study is that the ever-increasing cost of trying to stay mobile, independent and healthy, combined in many cases with the cost of reduced family income, has resulted in the financial cost of thalidomide-related disabilities increasing year on year.

## 2. About the study

Out of the 430 or so UK-resident thalidomiders, 80 took an active part in this study by providing full details of their expenditure on their own costs of thalidomide-related disability. All costs collected from these 80 individuals were then averaged over the 2 year period.

There is a well-established method developed by the Thalidomide Trust to grade the severity of disability levels of thalidomiders, and the 80 individuals from whom costs were collected are representative of all five bands.

An approximate description of damage typically found in the 5 bands in terms of congenital limb reduction defects is as follows:

- Band 1 – typical damage includes hand damage, triphalangeal thumbs, minor damage to hand and wrist;
- Band 2 – typical damage is forearm reduction, radial club hands;
- Band 3 – severe damage to a pair of limbs, may have internal damage;
- Band 4 – from complete absence of arms and hands, severe damage to more than 2 limbs, internal damage;
- Band 5 – typically severe damage to all 4 limbs, internal damage.

Thalidomiders recorded their costs across 7 main categories of 'health-related needs', which in turn are broken down into hundreds of sub-categories, giving an in-depth insight into the kinds of things that thalidomiders require in order to move towards an acceptable and equitable level of health, mobility and independence.

Full details of the profile of the participants in the study compared with the thalidomide community as a whole can be found in appendix 1.

## 3. Thalidomide damage and the consequences

On average, each thalidomider has more than six complex and chronic health problems from this list:

- Missing or shortened limbs and digits
- Spinal deformities and chronic back pain
- Arthritis, rheumatism, osteoporosis and sciatica;
- Muscular pain and strain, numbness and loss of function;
- Malfunctions of the kidney, heart and gastrointestinal tract;
- Hearing impairments and missing ears;
- Nose and throat problems;
- Poor vision and deformed eyes;

- Facial palsy;
- Epilepsy and obesity;
- Poor mental health and chronic emotional well-being issues.

A thalidomider with missing arms and legs typically has feet and hands attached to their torso. In childhood and young adulthood, they exhibited a surprising level of agility, shuffling along the ground on their buttocks and using teeth and hands to carry out many tasks for themselves.

Thalidomiders with two limbs missing or severely reduced – are the most prevalent group. Most of this group have shortened or no arms, with weak and twisted fingers, and no thumbs – many relying partially or entirely on their feet and teeth to do everyday things. Occasionally the main damage is missing or shortened legs, with a reliance on leg prostheses or wheelchairs to get around.

Those with sensory impairments, such as deafness or blindness or poor sight have specific additional costs related to their needs, such as for personal assistance when out and about and various forms of assistive technology.

Recent studies of thalidomiders' health highlight the increasing prevalence of late-onset health issues such as musculo-skeletal pain and wear-and-tear injuries, together with peripheral neuropathy, which is likely to be due to the age-related decay of already weak and damaged neural systems in thalidomiders.

Neurological decay is a prevalent late-onset symptom for the whole group, meaning numbness and loss of function of hands and digits, with concern that future neural decay will spread to cardiovascular and functional problems beyond the peripheral ones that are exhibiting currently.

The speed of decline is accelerating, and thalidomiders are experiencing step-changes in their conditions with compounded consequences for their ability to cope.

## 4. The Implications for Daily Living and their Costs

### (i) Mobility

A study of the health and lives of 980 German thalidomiders by Heidelberg University (Kruse et al, 2012) concludes that mobility is of central importance to thalidomiders. Having a car is described as a crucial 'part of the quality of life', and not just a means of transport.

The average disability-related annual cost of a UK thalidomider trying to maintain their independence and mobility is around £10,000 per annum.

- A motorised wheelchair with joystick steering for a four-limb deficient thalidomider costs up to £8,000 to buy it privately (this kind of wheelchair is not available from the NHS scheme).
- It is in constant use and it needs replacing every few years.
- The cost of maintenance and insurance adds a further £1,000 per annum per chair.

Most thalidomiders now rely on having more than one motorised wheelchair or scooter, so that when the main one used during the day is having its battery charged, the second can be used during the night for going to the toilet. Having a spare for emergency breakdowns is also a good idea when you are completely reliant on your wheelchair for your ability to get around.

A third lightweight foldable one is another typical purchase for taking on public transport or planes where heavy motorised wheelchairs cannot go.

A thalidomider who wants to drive a car and is missing any of their limbs, can do so today because of advances in technology; but it comes at a high price whether it be buying, leasing or through the Motability scheme. Getting a thalidomider on the road can cost up to £65,000.



Figure 1 - A steering plate for a thalidomider with short or no arms, costs around £6,000 with an additional £15,000 for other specialist controls and alterations.

A thalidomider with upper limb deformities, or no arms at all, cannot reach standard car controls so they require adapting to allow them to steer the car with their feet or fine-hand-controls such as joystick steering built close to their bodies.

Typically:

- Foot-steering plates cost £6,000;
- Joystick-steering £10,000;

- Remote controls for remaining car control functions, seating and seat-belt alterations can cost in excess of an additional £15,000.

Enabled to invest in a vehicle that is wholly suitable and modified to meet their special needs helps reduce further damage to thalidomiders' bodies.

Putting expensive adaptations into a second-hand vehicle does not make economic sense, as it is best to get long service out of car and adaptations together and avoid the expense of re-adapting too regularly.

It is most economic in the long run to buy a vehicle with functions such as electric windows and locking, automatic gears, push-button ignition and automatic rain-sensor wipers and parking sensors, as these help to reduce stretching and the strain on a thalidomider's body.

On average, automatic gears add on £1,500 to the cost of buying a manual car and the automatic rain-sensors, automatic head-lights and push-button ignition can add anything from £4,000 - £8,000 to the cost of buying a car.

The need for a vehicle large enough to accommodate a wheelchair, a ramp or hoist to get the wheelchair in and out of the car, means buying a van or large people-carrier, and all the upgraded features and bespoke adaptations on one of these can raise the total cost of getting a thalidomider on the road to £65,000.

#### *Personal stories*

*£19,000 for the car plus £9,800 to get it adapted so I can drive it.*

*"I have very short arms, and I have just bought a new car with foot-steering and other adaptations costing £19,000 for the car, £9,800 for the adaptations and £280 for the travel costs of getting the adaptations done in Yorkshire (my home is near Glasgow, Scotland so I had to drive to near Leeds and back 3 times to get the foot-steering sorted"). My cousin extended the handbrake and indicators for me for free.*

*"Annual servicing and maintenance of the adaptations is an extra cost of being disabled, averaging at £470 per annum, which is additional to the £536 cost of servicing/maintaining the standard parts of my car. I have to take it back to Yorkshire for the adaptations to be maintained every year"*

*My van and adaptations cost me £65,000*

*"I have no arms, hands or legs and my van is completely essential to maintaining an active life where I can involve myself with family, friends and everything that's going on.*

*Getting it adapted to allow me to drive with my toes is a long-winded and complex process, with a lot of attention to detail. However it is worth every penny to me and my family, otherwise I would not have much of a life".*



Figure 2 - A thalidomider using his electric-powered chair hoist to get into his electric joystick-operated wheelchair

*Wheelchairs are essential tools for independence*

*My spare £5,000 wheelchair means I can go to the toilet on my own at night.*

*“While the day-time chair is on charge during the night, having a second one means I can take myself to the toilet during the night, so I don’t have to wake my husband to help me. This one cost me nearly £5,000 to purchase, and will cost me £600 per annum to maintain, service and buy spare parts for it. It needs two new batteries every year - that alone costs £300, replacement tyres are £50 each. It costs £167 to insure it.”*

*My second wheelchair secures my independence*

*“I have no arms and no legs, and have just purchased myself a second joystick-operated motorised wheelchair to give me reliable mobility and 24-hour a day mobile independence. It cost me nearly £7,000”.*



As well as the more obvious aspects of independent mobility, thalidomiders have alternative strategies and costs of getting around. It is extremely difficult to take motorised wheelchairs on buses, trains or the underground, and thalidomiders with short or no arms to steady themselves are more likely to fall so are not able to travel safely on buses or elevators.

Many incur the high cost of taxis to get around to medical appointments, family visits, social activities and shopping trips, at an average cost of £112 per month.

Full details of the costs of maintaining independent mobility are in appendix 2.

## (ii) Maintaining a Home

The average 'extra' cost of thalidomiders running their own homes, or purchasing goods and services to increase their safety and independence in their homes is almost £17,000 per annum.

This category includes major adaptations, extensions, or specifically adapted rooms plus a wide variety of appliances and equipment.

Thalidomiders have found individual solutions to maintain a level of personal independence; for example, they have invested in items like adjustable-height tables, or kitchens and bathrooms with low and high fittings making them accessible to all members of the household.

Many thalidomiders have the need to improve their gardens for accessibility and safety reasons. Re-grading of slopes and surfacing paths for better accessibility, safety lighting and sheltered seating areas are amongst the investments made.

Figure 3. The bathroom of a thalidomider who has no legs, showing his near floor level basin alongside the normal basin for other household members with legs.



The closo-mat toilet is a crucial piece of equipment for all thalidomiders who have no or reduced reach (short or no arms) who are unable to clean themselves when toileting – it has a remote-controlled button to work a warm-water douche followed by air jets from the pan to dry the washed bottom.



Figure 4 Thalidomider demonstrating his closo-mat self-cleaning toilet and the electric-powered seat lift next to the toilet to allow him to get on and off himself



Figure 5 - A thalidomider with no legs and short arms shows his floor-level kitchen units. His kitchen is split between floor-level and normal height units and functions, although it is too small to provide full double functionality. He acknowledges that he and his family need to move to a larger house to provide the flexibility and space for his needs



Figure 6 - Electric light switches installed at a low reachable level. Note the door has been removed to accommodate a wheelchair, and shows the damage a wheelchair causes to paintwork – requiring extra and costly maintenance

*Personal story of a thalidomider*

*My hips are giving out because of shuffling along on my bottom for 50 years.*

*"I have no arms or legs, just hands and feet attached to my torso. I have lived in my 3-roomed Victorian flat for 20 years, and have had adaptations done to it several times, especially to the kitchen and bathroom. The pain I am in some days is incredible, I can't move or get out of bed, and my hips are giving out (because of shuffling along on my bottom for 50 years). I am increasingly reliant on using an electric wheelchair, and can see the day when I will not be able to move around the house in my usual way (shuffling along the floor). The bathroom doorway is not wide enough for a wheelchair to go through, and cannot be changed to allow that – so I am having to face up to the need to move house, to one where everything is accessible with wide doorways and corridors to allow wheelchair accessibility.*

*I cannot bear to think of the expense of this, but it is likely to be at least £150,000 for the house and tens of thousands of pounds for adapting the kitchen, bathroom and other accessibility aids - I wonder whether I will ever be able to afford it".*

*Personal story from a thalidomider*

*My future kitchen costs.*

*A kitchen has been installed for an upper-limbed deficient person at a cost of £8,000 in 2009. "To save on costs I re-used my cooker although that will need to be replaced within the next year or so and I re-used my old fridge. I therefore only had to buy a freezer, a dishwasher and obviously all the units, drawers and work surfaces".*

*It is an Ikea range of units made up of mainly wide drawers and open shelving, suitable for pulling out and use by the feet. The thalidomider acknowledges that using the units and drawers with her feet places heavy wear and tear on them, and that with increasing age and infirmity she will need to replace the whole kitchen with a bespoke-designed one with special appliances – perhaps at a cost of about £20,000 in a few years from now. "I may also want the option to move in the future, so that will mean adapting another house and kitchen."*

*Personal story of a thalidomider*

*It cost me £12,000 to help me work from home, I may have to add more bespoke features later on "As even simple things like travel and transporting files and a lap top were causing difficulties we had a loft conversion, so I could work from home. I identified that as one of my arms was six inches longer than the other, computer use was exacerbating my health problems.*

*We invested in voice recognition software and training which was yet another reason why a separate office was required (voice recognition only works if there is no background noise). I also needed a higher desk and a very low chair, which were not easy or cheap to source".*

*The cost of this was £12,000 for the bespoke-made work surfaces and shallow drawers, changing the electrics etc*

*In my experience I have to keep upgrading my home and working spaces as my needs get more complex, so I'm anticipating needing to spend more in the future."*



Figure 7 - With short arms, weak fingers, back and neck pain, a press-button key pad is much easier to use than having to bend and hold and twist a key. These cost on average £350 to buy and install

### *Thalidomiders' experiences of Local Authorities trying to get homes adapted*

Many thalidomiders are using their own funds to pay for home adaptations that should be paid for out of local authority Disabled Facility Grants (DFG).

- A thalidomider with very short arms and hip problems took out a loan to pay for a new adapted kitchen, ensuite bathroom, ramps and various access improvements at a cost of £120,000.
- Her local authority claimed that the cost and complexity of her needs meant that they could contribute only in a minor way, and they demonstrated a lack of awareness of her specific needs that she found unnerving.

Very few local authorities have any experience of providing bespoke home adaptations for people with very short arms or no arms – this is such a rare injury.

In another example:

- A thalidomider with very short arms and back problems was still waiting for an adapted kitchen after 4 years of unproductive negotiations with her Local Authority;
- These included 2 designs that would have resulted in a new kitchen that would have been inappropriate for her needs;
- The third attempt at a design for this thalidomider completed a bespoke kitchen solution at a cost of £59,000 to implement (installation and special appliances).

In this example, within 2 weeks of completion:

- Her back was less painful and she had more strength and energy to look after herself and felt able to contribute to community life again;
- Her use of prescribed painkillers has been reduced and she can, for the time-being at least, reduce her Direct Payments for help in preparing meals.

A typical thalidomide injury is having short or no arms, with reduction and lack of dexterity in fingers and no thumbs – one of the common difficulties this brings is with independent toileting. Most thalidomiders need a closo-mat or Geberit self-cleaning toilet, which for the remote-control versions cost around £3,500 plus installation, including a new electric connection in the bathroom. Some Local Authorities have helped with providing for these costly items, but many don't – one of the examples of 'post-code lottery' across the UK. In the 2-year study, 18 thalidomiders purchased a self-cleaning toilet for themselves, which suggests that Local Authorities have been reluctant or refusing to provide these crucial aids.

### (iii) Extra Living Costs

This includes the extra costs of pre-prepared food and ready-meals, higher-than normal heating and electricity usage, the extra cost of wear and tear on clothes, shoes and bed-linen, and the costs of buying-in paid assistance to run a thalidomider's home and outside spaces.

Also included are some particular ongoing household costs, such as toilet paper and wet wipes, plastic straws for 'no hands' drinking, or other household consumables where there may be a special disability need. These are small items but the costs add up.

Thalidomiders' bodies appear to have faulty temperature-control mechanisms thus relying on well-controlled house heating systems to enable them to cope with their internal swings in temperature. Some sweat profusely, which brings with it an additional cost of laundry and the cost of having a higher-than-normal supply of clothes.

#### *Thalidomiders' extra use of electricity and fuel costs.*

*"I have no arms and was struggling to use our coal stove that heated the house and gave hot water. I replaced it with electric heating such as under-floor heating, night-store heaters and panel heaters for extra heat. I've also a lot of electric gadgets to help me do things and kitchen appliances like a dishwasher. These have made life so much easier, but my electricity bills have soared – I reckon they have tripled to nearly £3,000 a year, but what can I do - I cannot go back to struggling with the coal stove and washing dishes with my feet up in the sink"*

#### *To keep warm my heating bills are twice as high.*

*"I'm no longer able to work, and am at home most of the time.*

*I need the heating on all day, as I get very achy and painful if I get cold, and because I use my feet all the time I wear flip-flops all year round (so my feet are accessible whenever I need them). This means my heating bills are very high, I have compared them with my neighbour's and mine are twice as high as hers."*

#### *I sweat so much I have extra fuel, water and laundry costs*

*"I sweat so much, I need 2 showers a day (instead of one or less). This means I have really high electricity and water consumption costs (I am on a water meter), with increased laundry costs of washing towels and clothes. I estimate the extra cost related to my disability is £700 per annum"*

*Personal stories of thalidomiders' everyday costs that add up.*

*£40 a year on straws so I can drink*

*"I am affected in all four limbs, and I buy about £40 worth of plastic drinking straws every year, something that normal people just don't have to buy.*

*Double costs of toilet paper and £70 on wet wipes.*

*"I have very short arms and I estimate I probably get through more than double what a normal person uses in toilet paper. I also need to use about £70 of wet wipes a year, just to have something easy to mop myself when I spill things or fall over."*

*Personal stories of 3 thalidomiders' extra costs of wear and tear*

*Thalidomider 1*

*My short arms cause me to have to replace clothes more frequently than I otherwise would and I have extra costs of making bespoke alterations to trousers and belts*

*"I have very short arms. I must use a dressing-stick with a curved 's' shaped end to pull clothes on, to tuck clothes in, or unravel them if they have rolled up too much (often the case with underwear). Sadly, the stick damages clothes, making holes - which mean the clothes become impossible to use as the stick just gets lost down the holes.*

*When I'm writing with a pen at work, the nib comes into regular contact with my shirts. After a short while these shirts are ruined because of the impregnated ink. Each replacement shirt costs £18 just to tailor the sleeves - over and above the cost of the shirt.*

*Also, I purchase more belts than an able bodied person. I pull my belt in my teeth to fasten my trousers - it draws the top of my trousers together so that I can fasten the hook and eye. This means 2 things - firstly, my belts become unsightly very quickly as they get covered in teeth marks and need replacing so I remain smart for work, and secondly, I must buy longer belts and have extra holes punched in them (at extra cost) so that they are long enough to hold in my teeth.*

*I use the belt loops on my trousers to pull them up. This puts a lot of strain on them - more than off the peg trousers will stand. My two options are to either buy more off the peg trousers as each breaks, or to have trousers made with extra strong belt loops.*

*Because of this the lifespan of my more expensive clothes is more limited than normal.*

*I need to buy 12 shirts every year, at a total cost of £490 including £220 to alter the sleeves*

*I need to buy 15 new underpants every year, at a total cost of £50*

*I need to buy 2 pairs of strengthened work trousers each year at a total cost of £150*

*I need to buy 3 strong/long belts a year at a total cost of £100 with extra holes punched"*



*Personal stories of 3 thalidomiders' extra costs of wear and tear - continued*

*Thalidomider 2*

*Having no arms mean I damage things and rip clothes and bed-linen*

*"I use my teeth and feet for everyday tasks and dressing myself. Using my teeth to dress myself and change our bedding, means I am continually ripping clothes and sheets. Because I carry everything against my chest, the rubbing and stains from this also contributes to my clothes not lasting very long. The cost of replacing clothes and bed-linen is at least £1,800 a year (it costs £300 just to keep replacing my damaged T-shirts every year)."*

*Dropping things constantly costs me £656 a year*

*Thalidomider 3*

*"I keep dropping things as I have increasing numbness in my hands and I have to replace crockery, equipment, even my laptop regularly – I also need to buy lighter pans and crockery so I can pick them up with less strain."*

Finally, costs were recorded of employing people to help thalidomiders run their own homes. For many this is essential as they cannot do tasks themselves, for others it is crucial to help them minimise the further damage, pain and tiredness of doing everything themselves, and relaxes their reliance on family members to help, with the knock-on implications for their own lives, including partners or spouses ability to work in paid employment.

*Thalidomiders' extra costs of running a home*

*I employ a housekeeper and others to help me*

*"I have short arms and am in a lot of pain nowadays. I employ a house-keeper to do all the tasks in my home that I cannot do no – she costs me £250 a week (that's £12,500 a year), but it means I can conserve my energy and body to do things I am good at, and stay living in my own home.*

*I spend extra on a gardener, window-cleaning, and a removals company comes and moves furniture when I want to spring-clean or change a room around. That's an extra cost of around £200 a month, but again, it stops me hurting myself doing things I am not fit to do"*

*My paid help keeps the family going and my husband can keep his job*

*"I have all 4 limbs affected, so I am reliant on others to do most domestic tasks for me – by employing a cleaner, handyman, gardener and someone to decorate the house, it means my husband can carry on working full-time, the house runs smoothly, and I can do the things that are important to me. It costs me around £400 a month for household duties, and about £280 a month for the heavier tasks – that's around £8,500 a year on those routine helps, a bit more for additional like cleaning the car".*

## (iv) Personal Care and Assistance

All the costs in this section are over and above what thalidomiders might receive from Direct Payments, the Independent Living Fund or any other form of Local Authority support.

For the 80 Thalidomiders in the study the average spend was £4,704 per annum.

As their ageing parents are becoming unable to cope, or have died, many thalidomiders are forced to arrange expensive taxpayer or independently funded arrangements for their care. In other instances, thalidomiders are trying to care for their own parents in their final years at huge cost to their own health and ability to cope with their own disabilities.

For many thalidomiders their partners or spouses and their children have provided a great deal of informal and unpaid care. As the children leave home the thalidomiders' families are left with the choice of either the high cost of buying in more care or their partners or spouses giving more support and care, thus restricting their own income-generating capability.

It is significant that 35% of the total thalidomide spend on paid and personal assistance was for personal care to help them with bathing, dressing and other personal and intimate needs, when this would normally be expected to come from Direct Payments.

### *Personal stories from 3 thalidomiders*

*Direct payments or Home-Care do not cover everything I need to keep my independence.*

*"I have very short arms, and I do receive some assistance from my local authority in the form of Direct Payments (of £515 per month). That pays for some of my most essential care needs at home, but it does not cover everything I need to keep my independence. On top of that I spend nearly £600 a month of my own money to buy in regular weekly help with cleaning, laundry and other household tasks, gardening and someone to accompany me on shopping trips and to go swimming. Otherwise I wouldn't be able to go out and about, as I cannot carry shopping, try on clothes, or change into a swimming costume without assistance. I have to pay for someone to do things like painting and decorating, cleaning windows or the car – things that other people can do for themselves, but I cannot".*

*"The rules on what my local authority will support are getting more restrictive as time goes on, even though my needs are getting greater as my body deteriorates. I find I am picking up the bill myself more, to the tune of at least £400 a month for all the kinds of help I need."*

*"I did have Home Care but couldn't cope with numerous staff changes and having to explain what my particular needs and difficulties were every time somebody different turned up. They way they changed their time slots all the time turned out to be nightmare, I couldn't cope with the chaos of it all - I had to cancel service, and I now pay £890 a month for people I can rely on".*

Due to the unresponsiveness of the system to deliver help when needed, one thalidomider who needed full time nursing care reported having had to take out a loan to pay the £750 per week (£39,000 per annum) they pay (privately) for home-nursing.

Another thalidomider with no arms pays £1,200 per month (£14,000 per annum) on top of Direct Payments for full-time personal assistance in her own home.

Other kinds of paid assistance include paying someone to accompany a thalidomider to do their shopping, or visits to the doctors or dentist.

Deaf and hearing impaired thalidomiders are having to pay for signers to help in situations where previously their children or parents would have helped, such as accompanying them to attend appointments, to go shopping or go out on social activities.

The minimum charge for a signer is £90 plus travel expenses even if it is just for a 5-minute appointment at the doctor's surgery.

*Personal story from a deaf thalidomider*

*It costs me £90 for a signer to go with me to the Doctors or the dentist or the Post Office.*

*"I am a profoundly deaf thalidomider, also with pain symptoms and fatigue. My family members have performed signing duties for me up until now. Now my children are adults and have left home, I need to find solutions to fill the gap – I employ a signer sometimes from the local Deaf Centre but I cannot afford this very often. For this, there is a minimum charge of 3 hours, which is £90 plus travelling expenses. This may be just for a 5-minute appointment. I try to co-ordinate appointments (for example, visits to the doctors, dentist, post office, bank) but this is not always possible.*

*My ideal solution would be to have a personal assistant (PA) who can also sign. This PA would help me with jobs around the house, accompany me on appointments, and also allow me to do more leisure activities to help my physical and mental well-being. Even if the PA is only employed for 10 hours a week this will be a major expense that I cannot afford. On top of the PA's salary there would also be travelling expenses – for example I would have to pay for the PA to go swimming with me, for my safety. A PA will also give me more confidence as I will get to know them and feel more comfortable for example, talking to a doctor about personal matters is easier with someone you know than with a stranger."*

Thalidomiders are increasing their use of other kinds of paid assistance to protect them from further wear and tear from using their bodies to do things they are not designed to do.



Figure 8 - Fifty years of excessive wear and tear on the bodies of thalidomiders with short arms reaching to do every-day jobs means they can no longer do ordinary daily tasks such as gardening, cleaning, and washing cars, etc

See appendix 7 for details of thalidomiders' costs of care and personal assistance.

## (v) Communications Technology

This covers all costs of using technology to keep in contact with the outside world, for example voice recognition software for thalidomiders with short or no arms, or touch phones, as normal mobiles are impossible to use with toes or twisted fingers. .

Average expenditure on communications technology is £1,267 per annum.

Mobile phones are a crucial aid to maintaining confidence and independence while out and about, and SatNav navigation aids are useful for people who cannot hold a map or atlas, because they have short or no arms.

Nearly every thalidomider participating in the study purchased an e-Book reader, as these are a practical solution to their difficulties with holding a book and turning pages.

For full details of the costs of Communications Technology see appendix 4.

### *Personal story from a thalidomider*

#### *The high cost of using technology for a deaf thalidomider*

*"I have invested in technology to help me know there is someone at the door and other light-up alarms. I have bought a computer and a licence to be able to run "talk by text" and "sign on screen" which allows me to communicate with my friends via a signer on line.*

*A 50-minute call costs £20.00. 50 minutes is not long when the signer, a third person, is involved.*

*I have also purchased an iPhone 4 so I can communicate on Face Time with family members and friends who can sign. The phone cost £500 and costs £35 a month for Face Time. The new computer has given me the chance to shop online rather than have the difficulty of shopping on my own or with the expense of taking a signer out with me.*

*I have invested £800 in CCTV around the house so I can see what the dog is barking at and to recognise people who are calling on me, together with £300 for vibrating mats near each external door with a sensor that vibrates when someone steps on the mat.*

*I have also bought (for £450) a vibrating baby alarm and screen so I can babysit my grandson."*

## (vi) Health and Dental Care

Thalidomiders' disabilities and health problems cannot be fixed. They need regular, life-long treatment for their unusual bodies with complex patterns of disability and accelerating deterioration. GPs and other health practitioners with little or no experience of thalidomiders' health issues struggle to find a treatment pathway.

NHS physiotherapy departments typically only allocate 3 or 6 sessions to treat a problem, whereas thalidomiders require regular and concentrated assistance to treat their chronic conditions. Consequently, thalidomiders have resorted to taking high-level pain relief and/or paying privately for physiotherapists, osteopaths, masseurs and other private treatments.

Thalidomiders also report self-financing counselling sessions for their emotional wellbeing and paying for their own limb prostheses, private consultations with neurologists and orthopaedic surgeons, and in some case paying for private procedures, because the NHS appears unable to provide solutions to meet their needs.

### *Personal story from a thalidomider - Laser eye surgery*

*Short arms and no thumbs means I struggle with contact lenses so I paid for laser eye surgery.*

*"I have been short-sighted for most of my life (from age 9). I wore gas permeable contact lenses from the age of about 20. These are uncomfortable and quite hard for me to clean. I couldn't consider disposables as I thought I would probably have problems getting them out of my eyes (they have to be "pinched" out – impossible with very short arms, no thumbs and fingers not properly jointed). My eyesight is really quite poor (-4 in both eyes).*

*I paid £3,100 to go privately to Optical Express for my eyes to be laser treated using the more expensive process called LASEK rather than LASIK, as it's less painful, recovery is quicker and aftercare is easier (putting in lots of eye drops, is not easy for us!)*

*Once I decided to have them done, I just wanted to get it done. I might have been able to get it done via the NHS but it would have taken a long time to get a decision, and I probably wouldn't have got it done with the process I wanted - I feel the £3,000 was well worth it for the results I've had. I now have more or less perfect vision - my close up is on a par with that of most 40-somethings, so all I need now is specs for very small type and reading books or menus if the lighting is poor."*

All thalidomiders rely on having to buy in medical services to supplement NHS services regardless of the severity of the disability they have. Treatments bought by thalidomiders include various therapies found to be helpful but of types not funded by the NHS. It is costing them on average £1,600 a year.

*Personal story*

*The cost of Titanium teeth implants and dental care*

*"I have no arms and no legs. When I was small, I was given leg prostheses to walk with. Well, I was forced to have them really. At school, the other children used to push me over, I was an easy target and with no arms to catch my fall, I smashed my front teeth out. For years I had trouble eating with so many teeth missing, and I use my teeth for picking things up and dressing myself. Dentures are just not a practical option for me.*

*Six years ago I spent £16,000 on titanium implants to replace 4 of the missing teeth (yes, £4,000 per tooth) and every year I get other teeth capped to keep a decent set intact, so I can use them for essential living tasks. Dental care is a major expenditure for me. I probably spend nearly £1,000 a year on care and capping now, including £230 just on regular 6-weekly dental hygiene visits. It's crucial that I care for my teeth, and it is really difficult for me to clean my own teeth properly. None of this is on the NHS, I pay for it."*

*Personal story from a thalidomider*

*Short arms mean I have over-used my back, neck and shoulders. NHS treatment is insufficient so I have to pay for my own treatment.*

*Private treatments for chronic back condition – "I have a very bad back, neck and shoulders now, from a lifetime of overusing these because of my short arms.*

*When I first started having problems with back pain and my back 'going' on me, I had treatment on the NHS from a local physio – but the referral times meant a wait of 3 months, then I would have 3 or 4 short sessions and they would stop and I was left to manage on my own. They gave me some exercises that worked for my lower back, but had no solutions for the neck or upper back problems.*

*I realised I had to find something better than this, to suit my whole spine and the fact that it is a chronic condition, so I visit a private osteopath a few times a year at £40 a time, a private physiotherapist specializing in back treatment – she costs £375 per consultation with £150 travel costs. I can only afford one session with her each year, even though it is high priority for me to see her. On top of that I get a massage every month, costing £60 a time, and Alexander technique lessons to teach me better postural behaviour, costing £45 per lesson, about six a year.*

*I spend more than £1,800 a year on these private treatment sessions, but I need to spend much, much more – what I get at the moment is minimal, I should be getting a massage weekly or fortnightly, or I would love to buy an electric 'spinal mobiliser' for daily sessions at home, but that costs £3,000 which I cannot afford."*



Figure 9 - A thalidomider receives Alexander technique lessons to improve postural behaviour after years of damaging her body by compensating for short arms

For full details of medical and treatment costs see appendix 5.



## (vii) Respite and Social Activities

Therapeutic respite is vital as it relieves musculo-skeletal pain and the general stress experienced by people in unremitting care situations.

Participation in social and fitness activities reduce isolation and improves mental and physical wellbeing.

Thalidomiders recorded an average spend of over £3,800 per annum on respite and hobby costs, plus £993 on social and fitness activities.

### *Personal story from a thalidomider*

*I needed a secluded break away from being stared at.*

*"I have very short arms and I was providing a lot of care to my sick parents, on top of my part-time job. I badly needed a rest and to spend time with my husband.*

*We spent three days in a small, secluded hotel with a pool big enough for me to exercise in, and I needed a room with a bath and a bidet.*

*I just needed to get away somewhere, where I would not be stared at or people commenting on my lack of arms – I have had a lifetime of that. The cost of the hotel was £1,123 and flights and car hire and other essentials added up to £986, an expensive break, but it enabled me to carry on caring for my parents when they needed me most."*

Respite costs for thalidomiders are high for a variety of reasons. Budget airlines and cheap last-minute holidays are not an option for thalidomiders as they have to plan carefully well in advance and pay for suitable accommodation and transport arrangements for wheelchairs, accessible accommodation.

They may pay someone to accompany them who may be a paid carer, which doubles the costs of travel, food and accommodation.

This will also apply for simply visiting a cinema or a swimming pool – a carer will have to accompany them and will need paying for.

Travel insurance for holidays is also higher for thalidomiders who have complex health problems.

### *Personal story from a thalidomider*

*I cannot afford to go away.*

*"I have no arms and no legs, and going away is so expensive for me, with the extra costs, that I just don't do it.*

*The last time I went away was 15 years ago, when I had a trip to New York. So I'm stuck in the house really, I have to put my efforts and money into essential survival living, and making do with what I've got."*

Thalidomide people are all in their fifties, which is a time when elderly parents may need care and attention as they age or become sick. Many thalidomiders report that they have extra cost implications of providing that care to their parents.

*Personal story from a thalidomider*

*The extra costs for 2 thalidomiders caring for their own elderly parents*

*"I have very short arms. My own home is designed and adapted for me, but going away is an issue as accommodation and travel needs to be suitable for me, especially now that I am getting less physically able. My Mum and Dad are now very frail and have a 24/7 care team with them in their home. My Dad was diagnosed with cancer in February, and has been given anything from 2 months to 2 years. My family and I are taking it in turns to visit them on a regular basis. The costs of this are high for me, as I need to fly nowadays (I used to drive or go by train) and to take my husband to assist me to help my parents (its important to me to be there, doing my bit regularly). The costs of each trip are around £1,500 for travel and a week's stay in a hotel nearby, which at 6 or 7 times a year - adds up to around £9,750 a year.*

*I am now unable to cope with my parents' dated home so we need to stay in a hotel with more modern facilities (especially bathroom and kitchen) and do not eat with my parents for two reasons. Firstly I cannot cope with staying in my parents' house, as I can't reach their taps, cooker, the kettle etc. so I can't even make myself a cup of tea! Secondly, the spare bedrooms are used by my mum and dad's live-in carers, so there is no room for us to stay there. This adds an extra expense of around £960 a visit for staying in a local hotel.*

*I had to buy a second car to help me care for my sick parents*

*"I have short arms with radial cub hands, and drive an adapted car. I bought a second-hand car for £3,000 and adapted it, so I had a second car. I could no longer drive from one end of the country where I live, to be with them – so the answer was to get the second car and leave it at my parents home, I can use the train to get there and have the car available for when I am visiting/caring for them. I need the second car there to help with hospital visits and shopping for my parents etc. I had to buy it, as I cannot just walk into a garage and hire a car like anyone else can".*

More than half of the study participants reported that participating in sporting activities is crucial for them (average £109 per annum) as are fitness activities such as pilates, gym sessions or employing a personal trainer (average £171 per annum). Many recorded the need to spend money on fitness equipment (averaging £160 per annum), which included the extra costs of adapting some of it to their special needs.

For full details of the cost of respite and fitness needs, see appendix 6.

For full details of the cost of social activities see appendix 8.

## (viii) Finances

The 'costs' presented in this study are likely to reflect more or less what thalidomiders have as financial resources available to 'spend' on their needs. In other words, they are spending up to the limits of what they are able to afford.

Some report that they have had to resort to various forms of credit, especially to pay for larger capital items such as cars, adaptations for cars, new houses, house extensions and major internal refurbishments including special adaptations for the home. Many anticipate they will need to make major investments in the future to pay for housing that will meet their needs for increased space and accessibility – their current homes being too small or inflexible for adapting properly, or for accommodating wheelchairs or live-in carers. Most will need to move to single-floor living in the next few years, with additional capital costs. This will happen suddenly as a result of major step-changes to their condition and ability to cope. Step-changes in needs require step-changes in costs, which are not matched by current income-streams available to the average thalidomider.

Thalidomiders come from all walks of life and have a variety of personal and family situations, which provide a backdrop to their ability to pay for their special needs and costs.

Around 50% of thalidomiders have been able to work for much of their adult lives, but in the past 10 years or so they have been exhibiting a decline in their ability to maintain their previous ability to cope with the rigours of paid employment. They have responded by cutting back their hours or responsibilities, or giving up all together - they exhibit a zest for life that is admirable, but with their health needs becoming more apparent as they age, they are slowing down and finding things take more time to do, and are becoming more difficult and painful.

In fact, 15 (19%) of the 80 participants in the Securing Our Future study reported a new loss or reduction of their earned income during the 2 years of the study, averaging a loss or reduction of £20,573 per person per annum.

This trend indicates a serious financial trend, including loss of earnings and loss of pension contributions.

### Thalidomiders are facing a very uncertain financial future

Because thalidomide-impacts have never been experienced before this generation, it is impossible to predict future prognoses or outcomes, but the subjective predictions are not good for these people. The best they can hope for is to manage their conditions to stem the decline by living well and being proactive in managing their bodies and environment, so as to prevent further damage as much as possible.

More and more thalidomiders will find it necessary to invest in products and services to cope with their disabilities. However, their mobility, independence and health will continue to be compromised by their finances. Some already need to move from two storey dwellings to bungalows but find it prohibitively expensive because of the cost of the necessary ground space.

There is also an issue of the caring being provided by family members, whether they are elderly parents, siblings, partners/spouses, or children leaving home.

The Director of the Thalidomide Trust reports that all thalidomiders worry about how they will manage as their health deteriorates as they lack options for increasing income or reducing costs.

## 5. Savings on public expenditure

The study provides examples of where a thalidomider's self-directed expenditure has made a saving on public costs. These are presented below as case studies, but their experiences can be extrapolated to a certain extent to the rest of the thalidomide group, as these people's health issues are typical manifestations of those shared by other thalidomiders.

The estimates of public cost savings from giving thalidomiders their own Health Grant are calculated from standard figures provided in the *Unit Costs of Health and Social Care* published by Personal Social Services Research Unit (PSSRU) of the University of Kent, and from the Department of Health's *Payment By Results Tariffs 2010-11* for hospital services and treatments.

For full details of how the calculations are made in the following case studies, see appendix.

### a. Cost saving case study 1

*Estimated saving to the NHS for one thalidomider = £8,900 per annum*

A thalidomider with very short arms spends:

- Nearly £2,000 per annum on preventative health measures (weekly massages, one-to-one pilates sessions, health supplements);
- £1,800 per annum on fitness-aids and activities (such as a foot-peddalling kayak she can use with very short arms, regular yoga classes).

These keep her fit and supple, and significantly reduce her need for standard NHS health care costs - estimated at the rate of saving £12,700 per annum on GP services, prescription painkillers, NHS physiotherapy and the estimated cost of a back operation she is keeping at bay (with inpatient recovery).

She is now using the knowledge she has gained by self-managing her own health condition, by offering massage treatments to others as a trained therapeutic masseuse. She delivers these massages with her feet, using a bespoke-constructed stool she had specially made for her, so that she can sit astride her patients at the correct height and position.

This not only keeps her in paid employment (a further saving on state benefits and makes her a net contributor to the UK economy) but keeps her strong, active and interested in the self-management of her own health.

## b. Cost saving case study 2

*Estimated saving to the NHS of one thalidomider = £8,911 per annum*

An upper-limb deficient thalidomider spent a month as a hospital inpatient a few years ago, due to extreme back and shoulder pain, with the loss of function of her arms. This stay allowed her to recuperate at that time but gave her no long-term solutions to prevent the symptoms from recurring.

She now spends £2,100 per annum on fortnightly massages and regular sessions with a trusted osteopath, which give her some relief from pain and she feels may be preventing further deterioration and emergency admissions to hospital.

These treatments reduce her need for standard NHS healthcare costs – estimated at £11,011 per annum, being the costs of GP services, NHS physiotherapy, prescription painkillers, and further long stays in hospital with extreme back pain and loss of function of her arms.

At today's prices, another month-long stay in hospital with a failed back would cost £6,960 in inpatient back care costs, plus £3,251 in musculoskeletal investigations of signs and symptoms as an inpatient.

## c. Cost saving case study 3

*Estimated saving in stated funded residential care = £23,000 per annum.*

A lower limb-affected thalidomider with severe learning difficulties and hearing/communication problems has purchased a leg prosthesis privately costing £4,000 which allows her to remain living with her elderly parents in their home, saving on the estimated £23,920 costs per annum of her needing to resort to full state-funded residential care – based on the cost of the leg prosthesis being amortised across 5 years).

## d. Cost saving case study 4

*Incalculable savings of mitigating risk and worry.*

A thalidomider with elbow-length arms and only one functional finger, fell over at home and broke one of her arms 6 years ago. Her home was not adapted for her needs and unsafe. She lost her independence completely for 5 months while it healed and incurred at least £12,000 on state-funded personal and health care during those months. She lost her part-time job as a result of the weakness in her arm, which never recovered fully - a loss of earnings of £7,200 a year since then. She has finally been able to start adapting her house (spending about £5,200 per annum on this) and now employs people to help with running her home (£4,000 per annum).

This has given her back her independence and means her husband and children no longer worry that she will have another debilitating accident. She is now confident enough to do voluntary work and may go back to paid employment.

## Appendix 1

### Bands of Impairment

The table below shows that the SOF study group provides a good representation of the thalidomiders in the UK, from the perspectives of both disability impairment band and gender, thus assuring that the SOF study findings carry integrity. Although Bands 4 and 5 are seemingly slightly over-represented, and Bands 2 and 3 under-represented – this has not skewed the figures significantly.

	Gender	Band 1	Band 2	Band 3	Band 4	Band 5	Totals
All UK resident Thalidomiders	<b>M</b>	25	59	71	38	27	220
	<b>F</b>	21	53	77	28	29	208
Totals		46	112	148	66	56	428
<b>Proportions</b>		<b>11%</b>	<b>26%</b>	<b>35%</b>	<b>15%</b>	<b>13%</b>	<b>100%</b>
SOF study participants: <b>2010/11</b>	<b>M</b>	4	9	11	10	6	40
	<b>F</b>	4	10	12	7	7	40
SOF study participants: <b>2011/12</b>	<b>M</b>	3	6	10	10	6	35
	<b>F</b>	6	9	13	9	8	45
Average over 2 years		8	17	23	18	14	80
<b>Proportions</b>		<b>10%</b>	<b>21%</b>	<b>29%</b>	<b>22%</b>	<b>18%</b>	<b>100%</b>

A few participants left or joined the data collection during the two years, but overall the proportions across the bandings and genders remained fairly constant.

## Appendix 2

### Independent mobility

The annual costs of trying to remain independent and mobile

*The average expenditure on mobility costs 2010-12 is £9,978 per annum.*

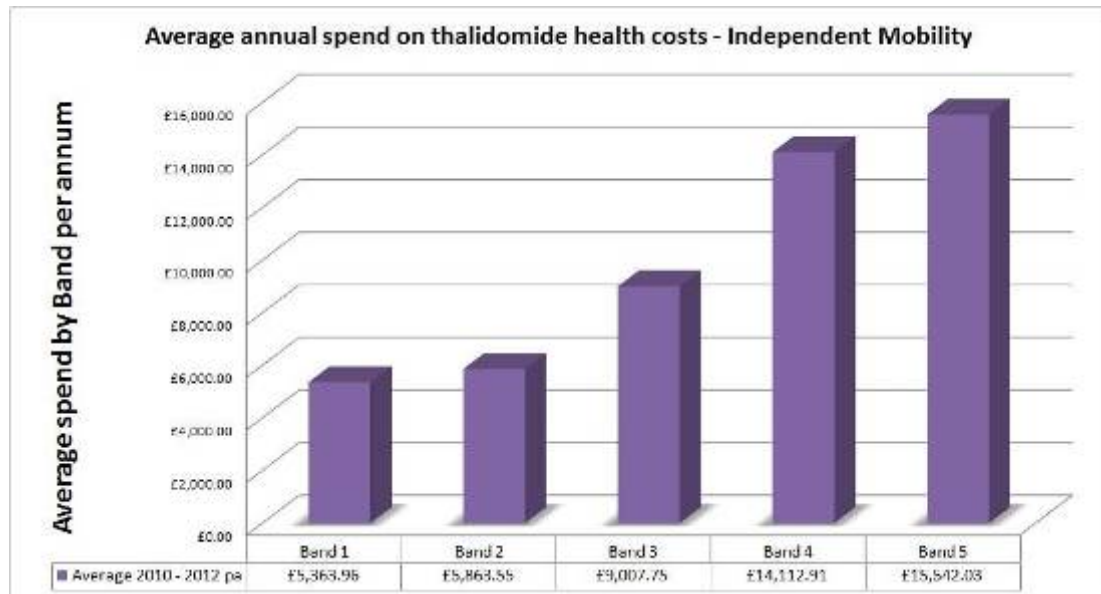


Figure 10 - The cost of independent mobility across all bands is, on average, almost £10,000

#### Key findings

Wheelchairs and electric scooters for 4-limb-affected and lower-limb deficient thalidomiders are an essential need, with 35 of these items being purchased in the 2 years of the study, at an average price of £2,667, the highest being £8,000. Some people stated the reasons for not being able to use an NHS wheelchair, such as unsuitable design and a tendency to cause pain or dislocations of joints when using them.

- The cost of maintaining wheelchairs and scooters, including the cost of buying replacement batteries every year, is an additional cost of disability which averaged £333 per annum with the highest being £1,650 per annum.
- The average cost of those who bought a car was £9,239, with the highest being £65,000 for a van with complex features and adaptations.

8 cars were acquired through the Motability scheme or by another kind of loan or credit arrangement, with the Health Grant being used for the deposit and payments to repay the finance plan (averaging £12,735 per person for these arrangements).

33 purchased car adaptations (separately from the car) the average cost being £5,545, with the highest recorded one-off cost of £50,000. This does not include the basic purchase price of the car.

1 person purchased a Speedy Duo, which is a hand-pedalled bike that fits onto a lightweight sports wheelchair, so that for the first time – they are able to join their friends on their outdoor excursions. The cost for the wheelchair is £1,595 and the hand-bike is £3,995, totalling £6,200 for the combination.

Nearly all thalidomiders reported the benefits of taxi's and Dial-a-rides, and cost of their regular use at an average of £112 per month, or £1,344 per annum.



## Appendix 3

### Home and specialist adaptations

*The average expenditure on home adaptations, equipment, and the extra costs of running a thalidomider's home is £16,859 per annum.*

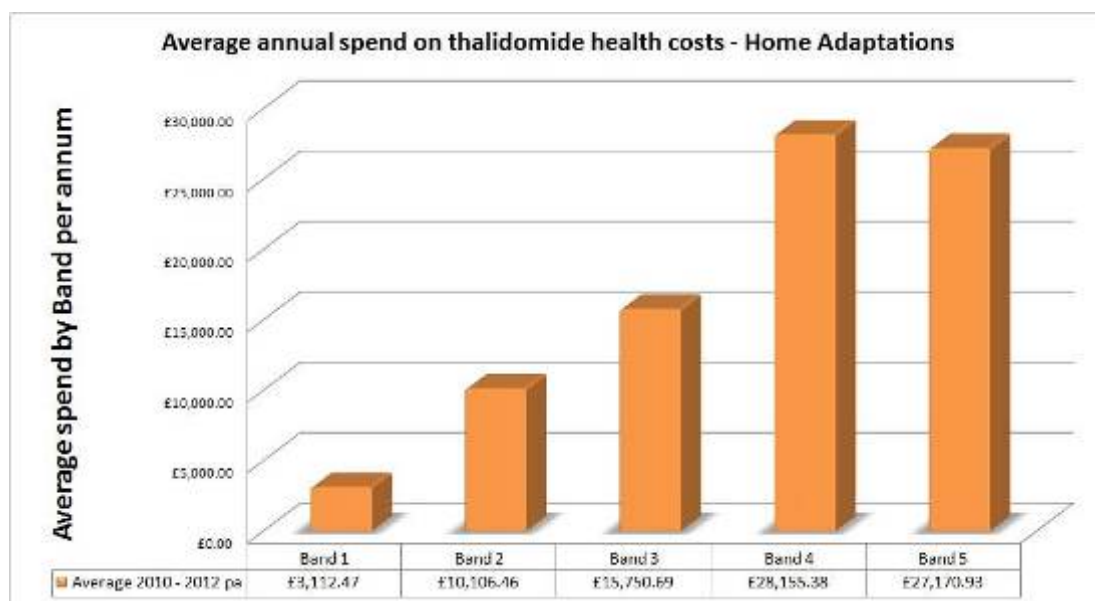


Figure 11 – The cost of home adaptations and equipment rises with each band group. Such was band 4's need that their expenditure in Year 1 has made their 2-year average higher than band 5's

#### *Key findings*

The highest average cost is borne by Band 4 people, and the lower expenditure in Band 5 may be explained by the likelihood that many band 5 beneficiaries have had by necessity a lot of home adaptations done before the Health Grant and paid for previously by loans from the Thalidomide Trust or family members, or other credit arrangements.

Another explanation for Band 4 being higher than Band 5 can be seen in the cost for personal care and assistance. Band 5 people have very high personal assistance costs that may include the extra costs of running the home (various kinds of paid help) integrated with the other costs of paid care and assistance. If they are not cooking for themselves there is no need to adapt their kitchen, or if they have paid assistance they have little or no need for dressing aids and so on.

Many thalidomiders in Bands 1 to 4 appear to be 'catching up' on making essential adaptations to their existing houses, after 50 years of making do with normal living arrangements and standard furniture items that have contributed to the deterioration of their health.

A small selection of costs is presented below. They are chosen to illustrate 'special' thalidomide-related costs or because they are typical expenditures being recorded for items where help is normally available from state or local authority funds:

- 13 people recorded the purchase of a new home built or purchased for their housing needs in the year, at an average capital expenditure of £99,631.

This might seem small for the purchase of housing in the UK, but this figure reflects in most instances the 'upgrade' capital costs of moving to a more suitable home.

Most of these thalidomiders report having to take out new mortgages or loans, or are borrowing from family, or the Thalidomide Trust - to pay the ongoing costs of moving home (or where they are extending existing homes), at an average cost recorded for paying back the mortgages or loans of just under £1,000 per month.

Nearly all thalidomiders in the study recorded some form of major work to their homes, ranging from:

- Extensions (average cost of £7,549);
- Heating improvements (average cost £736);
- Electrical works, such as moving switches, plugs to more accessible locations;
- Improved lighting (average £974 for indoors, or £276 for outdoor lighting);
- Nearly 30% of participants bought shower, bath or sink adaptations, at an average cost of £2,035, with the highest cost being £12,000.

Shower and sink adaptations are a crucial means of helping someone keep themselves clean in a safe and independent way – replacing a bath with a shower, raising or lowering a sink to the correct height and installing lever taps that are easy to turn.

- 14% of the participants bought a closo-mat or other self-cleaning toilet, at an average cost of £1,129.
- 3 people bought a body-drier as they struggle to use towels to dry themselves properly. The average cost of warm-air body driers was £662.
- 10 people paid for their own showering stool or bathroom grab rails, at an average cost of £135. These also should have been supplied by the Local Authority.
- Nearly 40% of the participants spent money on an adapted kitchen, averaging £10,500 just for the units (maximum £52,250), plus an additional average £2,025 for work surfaces, £607 for white-good appliances, many with special functions usable by those with poor dexterity or reach problems, plus an average of £1,290 for disabled-friendly cookers (typically ovens with telescopic shelves, touch-pad induction hobs etc).
- 30% of the group bought an electric gadget for the kitchen, in the category of a food-mixer, electric carving knife or can-opener – averaging £87, with the highest recorded £500.

- 13 people purchased remote-control electronic internal doors and window-opening systems at an average cost of £1,134 – useful for wheelchair users or with those with short arms who cannot reach or turn window or door-catches.
- 16 people bought electric outer or garage doors at an average cost of £2,052.
- 31 people bought outdoor ramps or grab rails for safety outside at an average cost of £2,036.
- 2 people purchased a stair-lift at an average cost of £3,825.
- 36 people bought an electric bed or a bed-hoist, at an average cost of £1,554.
- 51 people recorded the extra costs of wear-and-tear on everyday clothing, plus the cost of clothing alterations made to cut off sleeves, or patching or re-shaping, averaging £481 per annum.

The reasons for this are the tears and rips from using teeth and dressing sticks while dressing/undressing, and rubbing and staining of clothes from holding or carrying things against their bodies all the times (because of having very short or no arms to hold things away from the body). Bespoke alterations are needed to make standard clothes fit those with missing limbs or odd-shaped bodies.

- 5 people recorded an average extra cost of £600 per annum of replacing bed-linen, as changing beds with teeth and toes tends to rip sheets, and wear from excessive sweating is common (dysfunctional body-temperature control mechanisms is a typical thalidomide symptom).
- 6 people noted an average of £552 per annum, for replacing shoes that have been worn excessively or broken by pushing feet in and out of them constantly (because of using their feet and toes to do things).
- 13 people recorded the cost of replacing broken crockery (average cost of £30 per month), or other household items dropped because of their lack of dexterity or peripheral neuropathy.
- 11 people recorded expenditure specifically on removals costs, averaging £223 which included small-scale moving of furniture when houses are being re-ordered or re-decorated.

Nearly all thalidomiders recording expenditure in the 'homes' category, noted the costs of employing people to help them run their homes, ranging from an average of £346 per month on cleaning, laundry and other household duties plus an average of £304 per month on heavier tasks such as gardening, window-cleaning and handyman.

## Appendix 4

### Communications technology

Annual cost of communications technology to help thalidomiders stay in contact with the outside world and improve mental and emotional well-being.

*Average expenditure on communications technology is £1,267 per annum.*

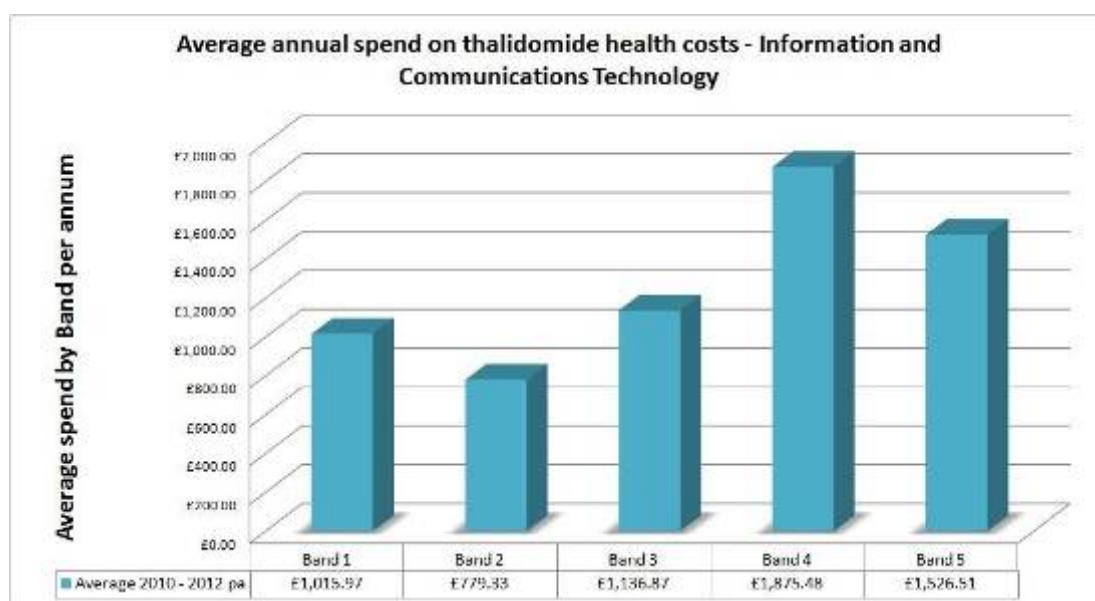


Figure 12 - The cost of technology to help thalidomiders stay in contact with the outside world

#### *Key findings*

The average costs borne by Bands 4 and 5 are much higher than Bands 1 to 3, suggesting that their communication needs are only fulfilled by the more complex and expensive forms of technology.

Nearly all of the study participants bought some form of computing hardware device, reflecting the importance of a computer or other technology in making their lives easier, relatively speaking.

- 14 people purchased adaptive software for their computers (voice recognition or screen-reader software) at an average cost of £230, the highest being £666.

Voice recognition software is crucial for allowing someone with short or no arms to work a computer without struggling to use a keyboard, which is damaging to posture and the health of neck and back, by too much bending.

- 22 people bought SatNav technology for their cars at an average cost of £264, as being deficient in upper limb use, using maps is difficult or impossible.

Nearly every thalidomider bought a Smart-phone or touch-pad Netbook at an average cost of £285 to buy, and £104 a month to run. These are especially suitable for use with poor dexterity, in that they can still be worked with a finger or toes.

## Appendix 5

### Medical and health costs (for services not already supplied by the NHS).

*The average expenditure on thalidomide medical and health treatments is £1,683 per annum.*

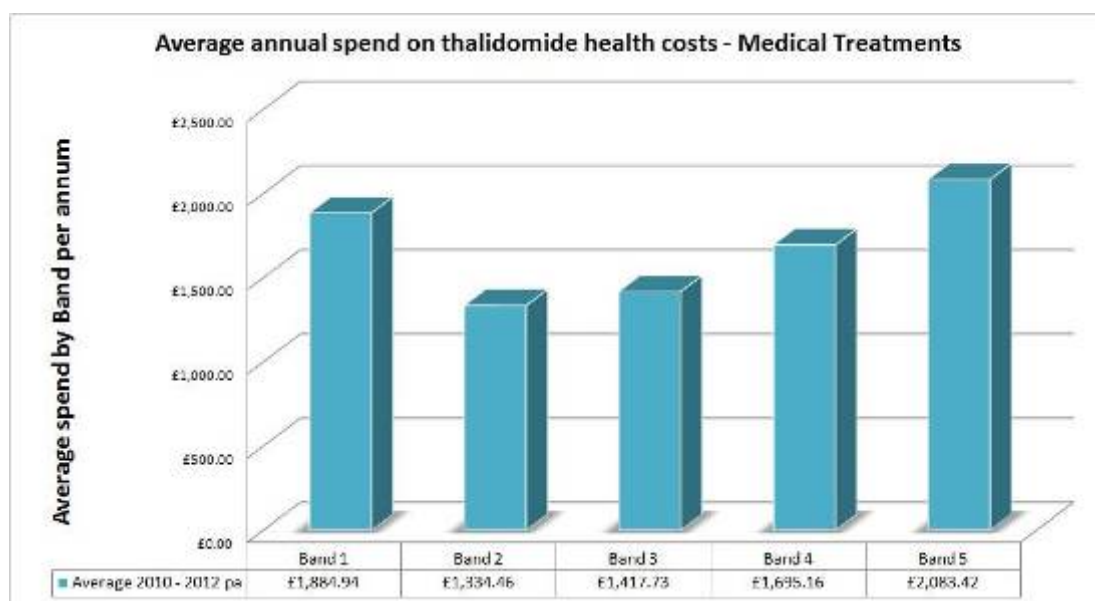


Figure 13 - The cost of medical and health treatments for services not supplied by the NHS

#### *Key findings*

All bands of beneficiaries rely on having to buy in medical and therapeutic services to supplement NHS services regardless of the severity of the disability they have.

More than 80% of thalidomiders in the study recorded spend on treatments, which included various therapies found to be helpful but of types not funded by the NHS, and the average spend on this category increased by 20% in Year 2 compared to Year 1.

Many thalidomiders now operate a high degree of self-management of pain and bodily dysfunctions.

The highest number of recorded instances of costs were for massages, chiropody and podiatry, osteopathy, eyesight and dental care costs.

- 70 people spent an average of £121 per month on massages, the highest spend on this was £1440 per annum.

This shows that nearly all thalidomiders (across all bands) use massage as a prime method of managing their musculo-skeletal pain and stiffness, and many report they feel they need more massage treatments than they can afford.

- 31 people spent an average of £125 per annum on osteopathy or chiropractor treatment– the highest expenditure recorded as £720 per annum.
- 25 people spent an average of £180 per annum on private physiotherapy, the highest being £1,080 per annum.
- 28 people recorded spending an average of £140 on a private consultation with a clinical consultant. One person spent £1,128 getting to and having a consultation.
- 31 people went ahead with private operations/procedures, averaging a spend of £1,930.
- 9 people purchased prostheses privately, at an average spend of £1,697, the highest being £8,000.

These gave the recipients a better quality of prostheses and more control over the fitting process.

- 45 people recorded expenditure on their sight/eye-care needs, averaging £175 per annum, the highest being £530.
- 38 people recorded major private dental improvement costs in the year, averaging £280 per annum, the highest being £3,000 per annum.

This is to be expected, given that thalidomiders use their teeth for many purposes, such as opening bottles, dressing themselves, carrying bags etc – many report having broken teeth, with the NHS not willing to pay for remedial work as it is regarded as an aesthetic issue.

- 28 people paid privately for therapy to aid their psychological/emotional well-being, averaging £167 per annum, up to the highest expenditure of £1,080.
- 25 people invested in the purchase of massage chairs, electric spinal mobilisers or hot tubs, averaging £810 per purchase. These items are useful to have at home for regular use at home, for daily treatment or management of a thalidomider's pain condition.

## Appendix 6

### Respite and fitness costs

The average annual expenditure on respite and fitness costs is £3,838 per annum.

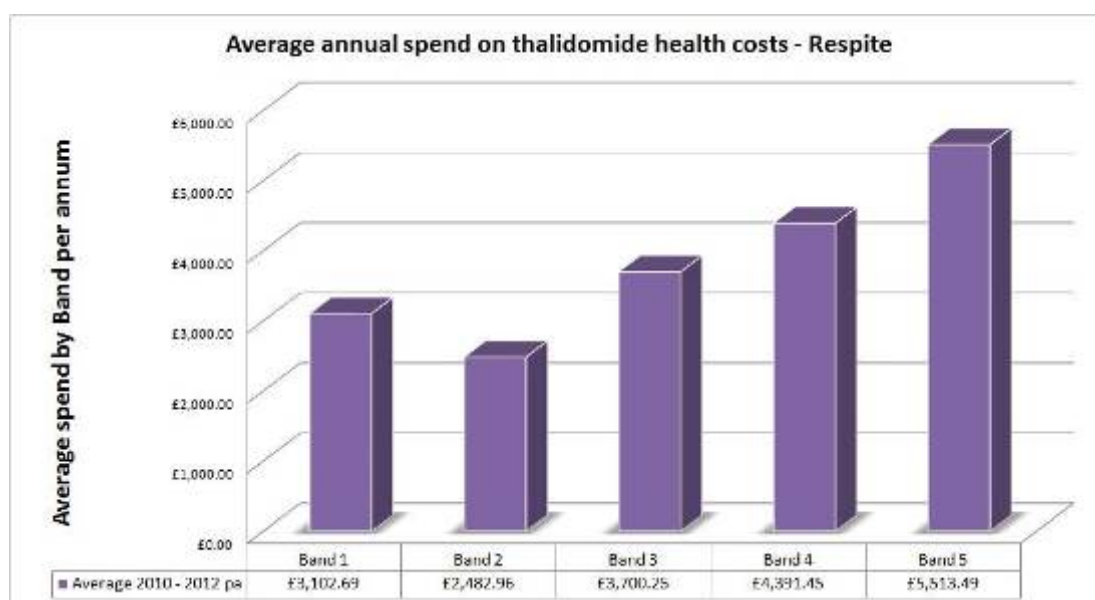


Figure 14 - The cost of respite to relieve pain and stress, by those in unremitting care situations

#### *Key findings*

Therapeutic respite includes trips away from home and relaxing activities that help to relieve musculo-skeletal pain and the general stress experienced by people in unremitting care situations. Regular fitness activity is included in this category.

Those with a higher level of disability have the added automatic cost of always having to take a carer with them on holiday doubling the travel costs and incidentals. Some have to pay extra employment costs for their PA companion, as they are 'on call' over the full period.

There are generally significantly extra costs to disabled people wishing to travel: cheap air travel is not accessible as budget airlines will not take wheelchairs; and they may have to pay extra for large luggage (medical equipment, extra clothing due to heavy wear, sweating etc). Disabled travellers tend to be forced to use expensive airlines such as BA, plus disabled people have to pay extra for their travel insurance.

The average trip away from home is recorded as £1,547, which includes transport and accommodation/food costs.

- 65 people recorded expenditure on regular fitness or well-being activities (such as gym membership, swimming pool, pilates or yoga sessions). The average expenditure on fitness sessions was £191 per annum, the highest £3,200.

- 49 people bought equipment or clothing for fitness or well-being activities, such as gym or pilates equipment, a second-hand foot-peddalling canoe, or running shoes: the average on this category of expenditure was £246 per annum, the highest recorded £1,700.

Another typical respite cost recorded was expenditure recorded for eating out, to mitigate the effort and pain of preparing meals – although the study omitted to include a cost category for this, 6 people recorded an average cost of £1,803 per annum for eating out. Reasons cited were because they couldn't cope with cooking and entertaining their friends at home, and eating out eases the pain and pressure of working in a kitchen unsuitable for my needs.



## Appendix 7

### Personal and paid assistance

Average annual costs of Personal Care and assistance over and above Direct Payments or the Independent Living Fund (these are discounted from the SOF figures).

*The average expenditure on Personal Care and paid assistance is £4,705 per annum.*

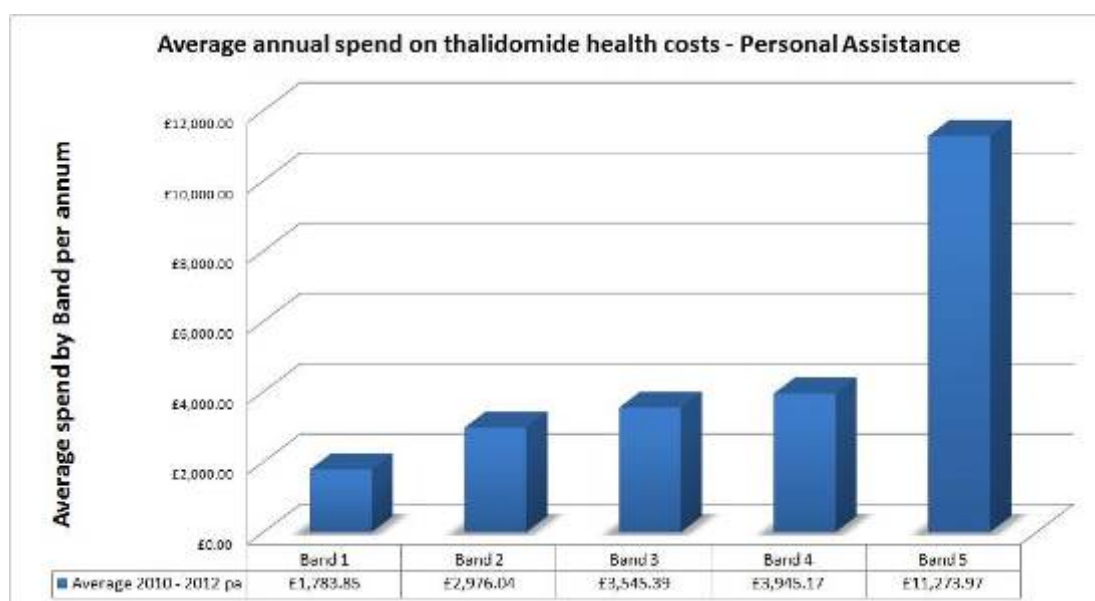


Figure 15 - The cost of Personal Care and assistance paid out over and above Direct Payments

#### *Key findings*

Expenditure by people in bands 2, 3 and 4 are similar with an average £3,488 per annum being paid for personal care and the costs of people to help them in ways that would otherwise involve putting their body at risk of further damage. The costs include paying someone to help them get out of the house, to help with shopping and trips to access essential services.

Some individuals in bands 3, 4 and 5 are paying significant amounts towards their Personal Care costs. This is on top of the Direct Payments they receive, which are inadequate to meet their needs.

Band 5 expenditure rises to an average of over £11,200 per annum as people in this group are likely to be using substantial amounts of their own money to buy in services they have always needed but not been able to afford within the maximum Direct Payment package they have been given.

## Appendix 8

### Social activities

Cost of social and fitness activity to reduce isolation and to improve mental and physical wellbeing.

*The average expenditure on social and fitness activity, and hobby costs was £976 per annum.*

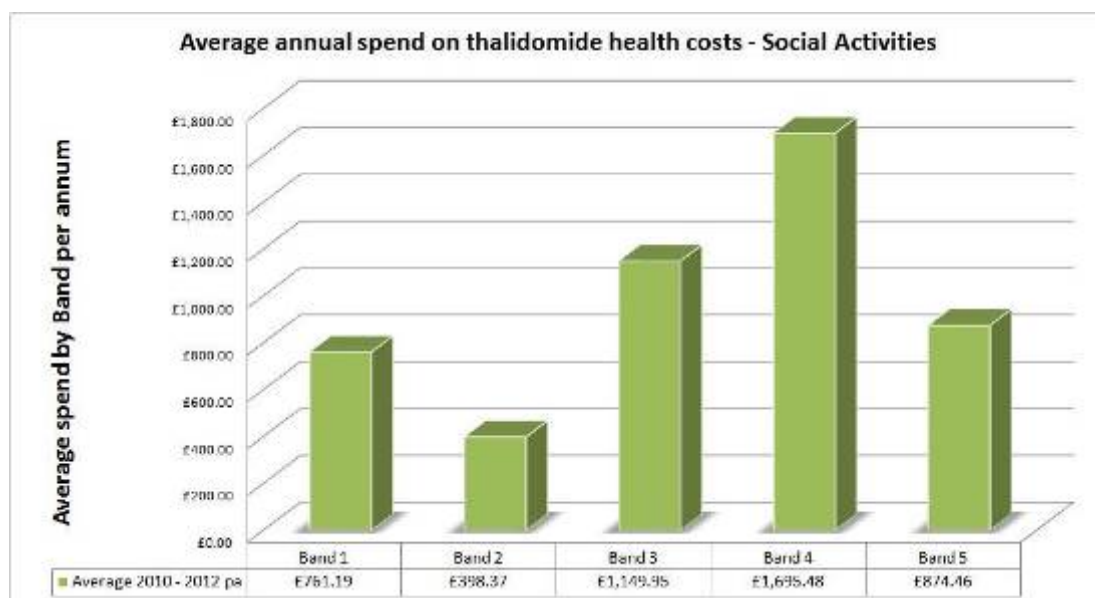


Figure 16 – The cost of activities to reduce isolation and to improve mental and physical wellbeing

#### *Key findings*

60% of the study participants recorded expenditure in this category.

Those that did not tended to be in Bands 2 and 5, which explains the lower average spend in these groups.

Those in Band 5 that did spend on social activity recorded some high costs, suggesting that these people cannot conduct social activities without the presence of a carer or family member, thus automatically doubling the costs for them of all social activities such as going out for a meal or attending a cultural event.

Buying equipment for hobbies was also a regular expenditure, averaging £694 per annum, rising to a maximum of £10,000 reflecting the expense of buying special equipment suitable for non-standard needs. Sometimes, equipment needs to be bespoke made or altered for the individual making it significantly more expensive than standard equipment.

Much of the remaining spend in this category was on membership fees of clubs and societies, subscriptions to magazines, visits to family and friends, and special interest trips or courses.