

# The **Thalidomide** Trust

## CHANGING LIVES – HEALTH AND WELLBEING SURVEY OF THALIDOMIDE SURVIVORS IN MIDDLE AGE

### BENEFICIARY SUMMARY

#### Introduction

In 2015 the Thalidomide Trust invited all 467 beneficiaries to take part in a survey to find out about YOUR current health and wellbeing, any problems you are currently facing and any (other) challenges you expect in the future. A massive three-quarters (75%) of you replied to the survey. This means we can be confident the survey gives an accurate picture of your current situation and future anxieties. Overall, we now have a detailed picture of the challenges involved in growing older with Thalidomide damage.

A full report of the survey is available and is published on the Trust's website.

#### Health problems

Most of you reported living with a range of health problems, on top of your original Thalidomide damage. Similar patterns have been reported by Thalidomide survivors in other countries like Germany and Japan.

#### ***Physical health problems***

Physical health problems are most common.

- Almost all of you (93%) reported pain or loss of movement in at least one part of the body. Back problems are most common, closely followed by pain in the shoulders and pain or loss of movement in the hands.
- Almost half of you also reported more general pain throughout the body. A quarter of you said this was 'severe and/or continuous' and another quarter described your pain as 'moderate and/or intermittent'. People in impairment Band 5 – ie with the most severe Thalidomide damage – were more likely to report general pain than the other Bands.

*“Chronic neuropathic pain .... both legs, below knee. 5 years. No cause found. Does not respond to treatment/pain management medication.”*

*“I have been suffering with regular bouts of pain in my side. I have had several tests done but I am told there is no conclusive reason for the pain.”*

- Two-thirds of you reported neurological symptoms like tingling or pins and needles and two out of five reported severe tiredness/fatigue. Fatigue was more common in Bands 1 and 2 (ie those of you with less severe impairments).
- A third of you, particularly in Bands 3 and 4, reported problems with balance or falls.

#### ***Mental health problems***

Many of you also reported some psychological problems. Half of you currently have, or have recently experienced, depression and/or anxiety. This is a much higher level than the UK population in general, but similar to the frequency of mental health problems reported in a recent study of German Thalidomide survivors.

#### ***Hearing, sight, dental problems and other health problems***

Problems with sight and hearing are common as people get older but even so, two-fifths of you said your sight was getting worse and over a third of you reported hearing/ear

problems. Just over a third said you had problems with dental health, similar to reports from Swedish Thalidomide survivors. You also reported a range of other health problems, all of which are common as people get older. Weight management, hypertension and bladder/continence problems appear relatively common concerns. Again this is in line with evidence from Thalidomide survivors in other countries.

On the other hand, one in five of you said your health or wellbeing had improved recently. The things that made the most difference were losing weight/healthier eating; medical treatments (e.g. pain medication/surgery); and exercise/therapy (e.g. massage).

*“I have enjoyed a huge improvement in my physical abilities and mobility from having lost a lot of weight. I have also experienced a reduction in my pain levels by exercising regularly and building lots of stretching exercises into my exercise regime. If I stop exercising for any period of time, there is a marked increase in my pain and increase in stiffening of my joints (back, neck, hips).”*

Many of you reported *several* problems with your health. Over half of you reported 5 or more current health problems; the average number of problems was 4.5.

### **Health and Social Care Services**

Given these health problems, it is not surprising that many of you reported using a range of services, although some of you said you had had problems getting the right treatment or care.

#### ***Use of health services in the past ten years***

Over two-thirds of you regularly have physiotherapy and/or use complementary therapies. Overall 17% of you reported recently having had joint or back surgery, including 6% who had had hip surgery and 4% knee surgery (compared to only 1% for both procedures in the general population aged 50 – 54).

Half of you take prescribed pain medication and/or use other pain-relieving treatments; both are more common in Bands 1 and 2. A quarter of you reported having (or recently had) treatment for anxiety and/or depression and a further 10% receive counselling for emotional issues.

#### ***Access to health services***

Two-thirds of you said you'd had problems in the past five years getting the right health care. You reported lack of knowledge or understanding about Thalidomide-related problems among health professionals; difficulties or delays in seeing a suitably experienced health professional; and delays getting treatment.

More positively, almost half of you thought your GP practice understands how your Thalidomide damage affects you. A similar number thought your GP would be willing to seek advice from a Thalidomide expert about how to manage your health problems.

#### ***Use of social care services***

Less than one in five of you are currently receiving local authority-funded social care (services or direct payment/personal budget). Even so, nearly half thought your current level of local authority-funded care was not enough for your needs; two-thirds are buying additional personal care or domestic help from your own income. Two-thirds of you without local authority-funded care are also buying help with household or personal care from your own income.

## Health-Related Quality of Life and Mental Wellbeing

Health problems, together with the treatment and care you receive, contribute to your overall quality of life. The survey asked several questions about your physical and mental wellbeing. We compared your answers with people in the general population in their 50s.

- In relation to physical health, the survey found you have significantly worse quality of life, compared to the general population of a similar age. In relation to mental health, your quality of life is also worse overall, but differences with the general population are smaller.
- Those of you with more severe Thalidomide damage have noticeably worse physical health-related quality of life.
- Those of you with less severe Thalidomide damage who are also unable to work because of disability or health problems have poorer mental health-related quality of life.

Over half of you said your general emotional wellbeing is worse or much worse than five years ago. A few (16%) of you reported feeling particularly isolated; people in this group tend to live alone and are unable to work because of disability or health problems.

## Homes and Cars

Most of you (87%) own your own home (a higher proportion than the general UK population aged 50 to 64).

- Almost a third of you are planning to carry out (further) home adaptations in the next year;
- Over 40% of you anticipate needing to move house in the next five years, most commonly to a home without stairs, a fully adapted property or a smaller house/garden.
- Nearly half of you currently have a specially modified car or van; a few of you expect to need (more) car adaptations in the near future.

## Work and Pensions

It seems that, over the past decade, your work situation has been changing more rapidly than people of a similar age in the general population. Overall, 59% (208) of you have changed your work situation in some way since 2000: almost two thirds have stopped working altogether and the rest have either changed jobs or reduced your working hours.

*“Injury to hand, equivalent of RSI – my physio told me I needed to retire, cannot afford to, but cut down.”*

Currently 41% of you reported being unable to work because of your disability or health problems.

Now just 37% of you are in work (full or part-time), compared to 82% of the general population aged 50 to 54. However, over three-quarters of you who are still in work expect Thalidomide-related health problems will force you to change jobs or stop work in the next five years.

*“Increasingly [affected] from 2002 onwards, at which time I was a Director of a limited company working in excess of 50 hours per week. I now struggle to manage 18 hours per week. I have now reached the point where stopping work altogether is imminent.”*

Just two-fifths of you have contributed to a private or employers' pension, which suggests that over 60% of you have no pension, over and above your state pension.

## Concerns for the Future

Most of you are worried about your worsening physical health. This means coping with both increased physical disability and pain, *and* the knock-on effects of deteriorating health on your family, independence, identity and self-esteem.

*“My only normal hand is deteriorating badly. I've had 3 operations on it, they can't do anything more. I'm in pain with it nearly all the time. I can't do hardly anything for myself now. I'm terrified. I'm only 55 – how much worse is it going to get? Having one hand I was never disabled but I am now. Luckily I have fantastic children who all automatically do everything for me that's needed. They cut my food up, do up my buttons, zips, and laces, and are amazing but I don't want to be a burden to them. Losing your independence is soul destroying.”*

Increasing difficulties in getting about, needing more personal and domestic help and worsening emotional health are further major areas of worry. Running through your comments was a common theme - that you feel your current way of life is quite precarious.

*“Because I live with my partner, I feel relatively secure. This year he had a cancer scare and though his results were negative I came face to face with the precariousness of my living arrangement. I would be in a disastrous situation if anything happened to him. I rely on him 100%.”*

## What next?

The Trust is extremely grateful to everyone who took the time to complete the survey. You have helped to compile very solid evidence on the changes and challenges of growing older with Thalidomide-related impairments.

The Trust will use this evidence in several ways:

- We will send the full report and a summary to the Departments of Health in England, Scotland, Wales and Northern Ireland. This will demonstrate to the Health Departments how you continue to experience growing health problems and how important the Health Grant is in helping meet at least some of your extra needs for services, special housing and mobility.
- The survey will be very useful in the Trust's current negotiations with Diageo.
- The Trust will use the survey evidence to develop its own services and support for beneficiaries – for example, we expect that more of you will need help with finding or adapting your homes in the near future.
- The survey also suggests topics that the Trust may need to investigate further – for example the difficulties some of you have experienced in getting appropriate health treatments, or help that might avoid falls or balance problems. The Trust and NAC is already following up one topic arising from the survey; we are investigating the earnings lost by people whose declining health forces them to give up work early and the impact on their income and pension. A report on this follow-up research will be published by the Trust later this summer.