

Health, Quality of Life and Employment amongst Thalidomide-affected People – Evidence from the UK

Introduction

There is growing evidence, both here in the UK and internationally, that Thalidomide-affected people are experiencing an increasing number of Thalidomide-related health problems as they age. It is also costing people more to live with these problems. The new ten year (2013 – 2022) Health Grant funded by the Health Departments in England, Scotland, Wales and Northern Ireland, is now in place. For many people it will be central in helping them to manage their changing health needs and maintain their quality of life. This summary brings together the main findings from research funded by the Thalidomide Trust in 2013/14. There were two parts to the research – a survey of the health-related quality of life and employment situations of all Thalidomide-affected people in the UK; and in depth telephone interviews with around 50 Thalidomide-affected people.

Findings

Health Related Quality of Life

- Thalidomide-affected people experience significantly poorer physical health than people of similar ages in the general population, and people with the more common disabling condition Multiple Sclerosis, especially around physical functioning and pain. Two-thirds reported their physical health was the same or worse than the lowest 2% of the general population.
- On average the mental health of Thalidomide-affected people is only slightly worse than the general population and similar to people with Multiple Sclerosis. However, 16% of Thalidomide-affected people had very poor mental health-related quality of life - the same as or worse than the lowest 2% of the general population.

Thalidomide-related Health Problems

The survey and the interviews showed that Thalidomide-affected people in the UK have growing concerns about their health. There were four main groups of Thalidomide-related health problems:

- **Reduced flexibility and mobility** - in particular reduced ability to reach, stretch, and bend. The causes of this varied but often seemed to be related to problems in the spine, joints and/or muscles. Many people reported facing difficult decisions about treatment (e.g. surgery to replace joints or fuse bones), whilst others were struggling to get a reliable diagnosis and clear treatment options.
- **Pain and stiffness** - reduced flexibility was often closely linked to increasing pain - more severe pain or pain in more areas of the body or pain being more continuous. Almost all interviewees said that their pain was made worse by everyday tasks such as using a computer keyboard, driving, housework etc.
- **Tingling and numbness** - around two thirds of the interviewees reported experiencing sensations such as numbness, tingling, and pins and needles in different parts of their bodies. For some this has resulted in a lack of functionality/grip. Most said that these were a relatively recent phenomenon (i.e. developing over the last five to ten years) and a number felt that they were getting worse.
- **Mental and emotional health** - a small number of people said that they had experienced periods of depression or low mood. Several people said that problems in managing their day to day activities, and the loss of independence linked to this, was affecting emotional health. For a few this came on top of more long standing emotional issues, often related to their Thalidomide damage.

Other health-related issues that were highlighted were tiredness and lack of energy; sight, dental and hearing problems; feeling hot and cold and weight management.

Employment

- Half of those responding to the survey said that they were unable to work because of their disability or health problems
- Of those working full or part-time, the majority said that they had to work to maintain their standard of living, although half of them said that working was making their health worse
- Around a quarter of people in the survey said that they had changed their job or the type of work they did because of their disability or health problems
- There was a jump in the number of people who stopped working or reduced their working hours after 2012 – possibly because having the Health Grant meant that those people who no longer felt able to work could afford to stop, whilst others were able to change their working situation to ‘preserve’ their health.

Concerns about the future

Thinking about the future, people were concerned that their ability to work was declining at the same time as the cost of managing or coping with their Thalidomide-related health problems and disabilities was increasing. The biggest worry was that poorer health would lead to them being more dependent on their family (at a time when many peoples’ parents were aging and/or adult children leaving home, with the loss of the help that both had previously provided), paid care workers and/or equipment. A number of people were thinking about moving to a more manageable property but the cost of both buying and adapting a new home was a concern.

Ten Year Health Grant – Current Use

Those interviewed were asked about the main ways in which they had used their Health Grant in 2013/14. Most clearly saw their Health Grant as money to be used for their health and well-being, and their spending fell into the following broad areas:

- **Self-management of health problems** including private health care (e.g. private physiotherapy/massage) and dental care not available on the NHS to address their complex and deteriorating health needs
- **Home maintenance and adaptations and mobility aids** (both transport and wheelchairs) to take account of reduced flexibility and mobility
- **Domestic help and personal care** – particularly to fulfil tasks that they are unable to perform due to reduced flexibility, loss of grip and fatigue; or to replace unpaid support from family members.
- **Respite/holidays and social activities** to help address isolation and improve mental and physical wellbeing
- **Off-setting a loss of income combined with the higher costs** of living with Thalidomide damage.

The research was commissioned by the UK Thalidomide Trust and carried out by Firefly Research.

A full report of the research is available at: <http://tinyurl.com/mxtnflw>