

LOSS OF EARNINGS AND PENSIONS AMONG UK THALIDOMIDE SURVIVORS

Executive Summary

Thalidomiders' working lives

The 467 beneficiaries of the UK Thalidomide Trust¹, now in their 50s, are experiencing consequential Thalidomide damage² that is having an increasingly severe effect on their working lives, incomes and future pensions.

The original compensation settlement between the (then) Distillers Company and parents of Thalidomide children reflected the lower expectations of the early 1970s about the potential education and career achievements of disabled people. In actual fact, UK Thalidomiders achieved very similar patterns of educational qualifications as their general population counterparts. Moreover, apart from a very small minority of the most severely disabled, the vast majority of Thalidomiders have been economically active for much of their adult lives, in a wide range of manual, professional, senior management, clerical and IT-related occupations including: postman/delivery driver; HGV driver; production line worker; consultant clinical psychologist; senior child protection officer; local authority IT training officer; specialist sensory impairment social worker; specialist teacher; bank call centre advisor; medical secretary; hospital ward clerk; payroll manager; computer programmer; data entry assistant; police CCTV operator; telecoms software engineer. Many, particularly those with less severe impairments, have pursued professional careers. However, beginning in their early 40s, increasingly widespread and severe consequential Thalidomide damage is now forcing Thalidomiders to reduce their hours of work, switch to less demanding (and less well remunerated) jobs or give up paid work altogether.

Currently, only just over one third of Thalidomiders are working, either full or part-time. This is in striking contrast to the general population aged 50 to 54, of whom 82% are in full or part-time work. Conversely, only 18% of the general population aged 50 – 54 are economically inactive, compared with 63% of Thalidomiders. Moreover, of those Thalidomiders who are still in work, a much smaller proportion are working full-time, compared with their general population counterparts, but much higher proportions are working part-time. The contrast with the general UK working population aged 50-54 is particularly striking for men, with male Thalidomiders being six times more likely than men in the general population to be working part-time. Female Thalidomiders are also much less likely to be working full-time, but over twice as likely to work part-time, compared with working women in the general population³.

It is recognised that Thalidomiders are unique group of individuals, who have been supported by the Thalidomide Trust for much of their lives and their experiences may not be representative of the experiences of everyone ageing with a disability

¹ The vast majority of Thalidomide Trust beneficiaries currently live in the UK; a very small number, whose mothers took Thalidomide distributed in the UK by the Distillers Company, currently live overseas. The term UK Thalidomiders is used throughout this report to refer to the entire group of Trust beneficiaries, on whom this study is based.

² The term 'consequential damage' is used to describe the pain and other symptoms that Thalidomide survivors now experience as a result of their original Thalidomide impairment.

³ <https://stats.oecd.org/>

Changes in work status

A representative survey of UK Thalidomide survivors shows that consequential damage has forced three out of five to change their work situations since 2000; at that time they were in their early 40s, some 25 years before statutory retirement age. Over three-quarters of Thalidomiders in severity Bands 1 to 4⁴ were working prior to 2000, but by 2015 less than half were in work.

Changes include giving up work altogether, reducing working hours or changing to less demanding jobs. Those with less severe impairments are more likely to have reduced their working hours or changed to less demanding jobs (at least for the time being). Those with more severe impairments are more likely to have stopped work altogether. As severity of impairment increases, the proportions still working gradual decrease.

Invariably these changes were prompted by increasingly severe consequential damage:

I've just this week dropped my working hours down to 2 days a week as I am suffering severe pain in my spine. I'm not sure if even 2 days a week will help (woman, Band 2, NHS specialist speech therapist)

I left [former employer] in part so that I would have more autonomy over my working pattern and am now able, for example, to rest during the day if necessary (man, Band 5, former senior journalist, now self-employed consultant)

I can no longer do any work due to pain (man, Band 1, former office manager)

Due to my own fight for independence and trying to live a normal life, I have risked my body to the limits and now I'm 56 years old and things due to my Thalidomide damage have made it impossible to carry out working and being able to look after myself with everyday tasks and personal hygiene has become a struggle (woman, Band 1, former apprenticeship assessor who reduced her working hours before stopping altogether)

Thalidomiders with more severe impairments are less likely to in work (and, if they are, less likely to be in full-time work) than those with less severe impairments. Men and women with degree-level qualifications are also more likely still to be economically active than those with no qualifications.

Impact on earnings

Thalidomiders across all severity Bands report reduced earnings:

I took ill health retirement from my main employment circa 3 years ago. I get a pension from that. I was an HR director. I currently do part-time work (2-3 days/month) as an employment tribunal member. [I currently receive] £180 plus expenses per day.... As HR director it was 50-60 hours per week, £95,000 per annum (man, Band 2)

⁴ When the original compensation agreement was made between the Distillers Company (which distributed Thalidomide in the UK) and the Thalidomide Trust, each Thalidomide survivor was assessed to determine the severity of their Thalidomide impairment. This assessment – termed the 6(iv)b figure (reflecting the clause of the agreement) - determined the level of compensation they would receive. The compensation is paid as an annual grant by the Thalidomide Trust. Since 2010 the 6(iv)b figure has also determined the level of the Health Grants paid through the Trust to Thalidomiders by the UK Departments of Health to meet their exceptional health needs. For convenience, the individual 6(iv)b figures are clustered into 5 Bands, from Band 1 (least severe impairments) to Band 5 (most severe impairments).

..in recent years [I earned] under £5,000. However, up to 2006/07 my income was between £40,000 and £60,000.... I have just stopped and will draw down a small pension in September (man, Band 2, self-employed print delivery firm)

Methodologies used to calculate lifetime earnings losses for personal injury compensation claims were applied to the employment and earnings histories of seven exemplar Thalidomiders.

Table S1. Lifetime earnings losses of seven exemplar Thalidomiders

	Lifetime earnings loss without interest	Lifetime earnings loss with interest on past losses added
Woman, impairment band 1 <i>Team manager in a bank, reduced hours full to part-time before stopping work in 2011</i>	£285,657.74	£287,730.16
Woman, impairment band 2 <i>Specialist teacher, reduced hours full to part time before stopping work in 2014</i>	£418,631.32	£427,526.07
Woman, impairment band 3 <i>Project manager; long periods of sick leave before stopping work in 2016</i>	£582,830.18	£600,827.61
Man, impairment band 3 <i>Factory worker, made redundant 1990 and subsequently retired on health grounds</i>	£575,381.55	£851,806.09
Woman, impairment band 3 <i>Speech and language therapist; currently working part-time; expects to retire 8 years before statutory retirement age</i>	£317,154.94	£317,505.77
Woman, impairment band 4 <i>Clerk, retired in 2005</i>	£294,014.15	£323,719.79
Woman, impairment band 5 <i>Clerical assistant, reduced hours 1996 and retired 2010</i>	£392,894.51	£400,004.05

Although these case studies are not necessarily representative of all Thalidomiders, there appears to be no clear relationship between severity of impairment and lifetime earnings losses.

Impact on pensions

Reduced hours and early retirement affect future pension entitlements. Less than two in five UK Thalidomiders have contributed to private or employers' pensions; over 60% will rely only on their state pension, a far higher proportion than the general pre-retirement population. Those with more severe impairments are less likely to have contributed to private/employers' pensions.

Even among those with an employers'/private pension, anticipated entitlements have been reduced by early retirement:

My pension is based on 23 years service rather than the 40 I should have worked (woman, Band 1, former call centre team leader/manager)

It [pension] has already been capped and I can access it now but it will be a fraction of what I should be entitled to at 60 (woman, Band 2, former special needs teacher who moved from full-time to part-time teaching before stopping work altogether)

Others referred to the effect of reduced earnings on pension entitlements:

If I could have got higher paid positions, it would have made a difference to what I could have saved (woman, Band 1, former financial services administrator)

Yes [my pension has been affected] purely due to earnings being low and having to give up my personal pension at one point, then being so far behind I never re-started it (man, Band 4, self-employed selling electronic components)

A few noted that reduced earnings meant they had simply been unable to afford to contribute to an employers'/private pension:

As reduced hours, I felt I could not continue to contribute to pension as required my salary (woman, Band 3, senior speech/language therapist)

Relationships between work and health

Relationships between Thalidomiders' work situations and physical and mental health are complex. Those who want to work but are unable to have the poorest mental health-related quality of life. Those who have chosen not to work for health reasons have the best mental health-related quality of life – albeit below the general population average. Among Thalidomiders with less severe impairments, many of whom have been able to pursue normal careers and earnings patterns, giving up work appears to have damaging consequences for their mental health-related quality of life, as does continuing in full-time work despite deteriorating health:

I found it very difficult to accept that I could no longer work. I don't think I was depressed exactly, but it was a close call and I was lucky to be able to find a voluntary job to get me out (woman, Band 1, former customer services advisor in bank call centre).

I loved my work. I really miss it. I was ill and struggling when I came out of work in 2004, using large amounts of painkillers and not understanding why my body was collapsing and in so much pain. Psychologically it has been a catastrophic disappointment that I cannot work and I have lost a lot of confidence since then and have been using counselling and psychiatric services regularly since (I did not need these previously) (woman, Band 3, former university project manager)

Thalidomiders unable to work because of poor health tend to have markedly poorer physical health-related quality of life. Conversely, those still working full-time have better physical health-related quality of life, as do those with lower levels of impairment who have chosen not to work to protect their health. Nevertheless, again their average health-related quality of life is significantly worse than for similar aged people in the general population.

Future work plans

More than two-thirds of Thalidomiders in severity Bands 1 to 3 expect to make (further) changes to their work situation during the next five years (again well before statutory retirement age). Fewer Thalidomiders in Bands 4 and 5 expect to make changes, but only a quarter of them are currently working anyway:

Finding it more and more difficult to keep job due to the pain my hands and forearm (man, Band 1, telesales advisor)

Highly supportive employer but poor mobility, pain and exhaustion now forcing me to consider giving up my post and working as an independent consultant for the same organisation [leading to] loss of earnings (woman, Band 3, now working 15 hours a week as senior fostering and adoption practitioner)

The impact of Thalidomide on family members' employment and earnings

There is some evidence that consequential Thalidomide damage is also affecting the employment and earnings of other family members, as recent deteriorations in health have prompted decisions by partners to reduce their work commitments:

My husband went part-time 10 years ago as I needed more help with daily living tasks (woman Band 5, gave up local authority clerical job)

My husband 'retired' early to be more with me (woman, Band 5, gave up work as computer programmer)

Lifetime discrimination

Thalidomiders drew attention to disadvantages experienced throughout their working lives that had affected their employment opportunities and earnings. UK Thalidomiders have very similar patterns of qualifications as the general UK population of a similar age, so these disadvantages did not reflect lower overall educational attainments.

Pain, discrimination and various psychological barriers have always placed me at a disadvantage (man, Band 3, now self-employed trainer/coach)

Some Thalidomiders had been unable to pursue desired careers. One Thalidomider (Band 3) was told she could not train as a doctor and, although she had a successful career in an alternative field, was nevertheless estimated to have lost earnings of £1,221,533.22 (if she had practiced as a physician) or £1,666,704.31 (if she had progressed to consultant status). Another (Band 5) was estimated to have lost £742,580.30 (£555,607.00 net) in lifetime earnings because she had worked as an audio-typist rather than the speech therapist she wanted to be.

Others reported difficulties (re)entering the labour market. One man (Band 3) was out of work for 3 years in his early 20s, despite attending over 100 job interviews. His lost earnings, estimated on the basis of his last wage (less tax and NI), were £38,152.32.

Some Thalidomiders reported a lack of appropriate workplace adjustments that contributed to decisions to stop work well before retirement age:

Had they [employers] supplied me with the adaptation Access to Work suggested so I did not have to bend right forward to see the screen and suitable trolleys for moving coinage, it would have been unlikely I would have had back problems at 37 years old (woman, Band 4, former customer services advisor)

I stopped working because of pressure of having Thalidomide in the workplace. Could not go to the toilet in the time allocated to people (man, Band 3, former mortgage customer service advisor)

Finally, a number of Thalidomiders reported experiencing general discrimination against people with unusual, visible impairments

While my disability is not major, it is visible and prevented me from becoming a manager in [major national retail chain]. I have evidence to prove this (woman, Band 1, former financial services administrator)

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The full report can be downloaded here: [insert url]