

Executive Summary

Thalidomide-impaired people: quality of life

A Community Fund project on behalf of The Thalidomide Society



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ISBN: 1-872707-16-5

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- Encourage and help providers of health care to put patients' needs first
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About The Thalidomide Society

The Thalidomide Society was formed in the UK, in 1963, by parents of thalidomide-impaired children in order to help and support the affected families and to campaign for public support and recognition of what had happened.

The Society aims to:

- Raise awareness of the problems experienced by thalidomide-impaired people
- Facilitate the exchange of practical experience and medical good practice for all thalidomide-impaired and similarly disabled people.

The Society provides:

- Aid and support
- Advice and information to all thalidomide-impaired people and their families through a network of user-led contacts, regular newsletters, workshops and seminars.

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Acknowledgements

There are a number of people and organisations we want to thank for their support and contribution to the project:

Thalidomide Society, especially:

- Vivien Kerr: Co-ordinator
- Simone Baker: Assistant Co-ordinator
- Marie Pearse: Former Chair

Thalidomide Trust, in particular:

- John Hurley: Assistant Director
- Neil Buckland: former Director
- Martin Johnson: Director
- Staff who administered the mail-outs

College of Health staff, especially:

- Francesca Avbara: Training and Marketing Officer
- Barry Kelly: Research Assistant
- Fatema Hussain: Research Assistant
- Pat Whalley: General Office Manager
- Shade Aderibigbe: General Office Administrator

Thalidomide project telephone interviewers

The project Steering Group:

- Vivien Kerr: Co-ordinator Thalidomide Society
- Graham Kelly: Researcher BMRB & member of the Thalidomide Society
- Anne Horton: Occupational Therapist & member of the Thalidomide Society
- Professor Richard Smithells: Emeritus Professor & Thalidomide Trust board member
- Ian Flack: Business Manager College of Health
- Fiona Carnegie: Senior Occupational Therapist, Roehampton Rehabilitation Centre
- Marianne Rigge: Director College of Health

Rosaleen Moriarty-Simmonds who provided the project team with disability equality awareness training.

Eddie Freeman for designing and drawing the cartoons.

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All the Thalidomide Trust beneficiaries who gave up their time to take part in the research and shared their views and experiences with us.

Project Team:

- Jessica Bush: Project Manager
- Marcia Kelson: Research Supervisor
- Catherine Kennelly: Lead Project Researcher
- Jacque Riesel: Research Assistant and Administrator

Summary

This is a summary report of a project to investigate the health quality of life of thalidomide-impaired people. The project was carried out for the Thalidomide Society by the College of Health with funding from the National Lottery Charities Board, now called the Community Fund.

Introduction

This study was undertaken in response to emerging anecdotal evidence from members of the Thalidomide Society and the Thalidomide Trust about deteriorating health and physical problems.

The aim of the project was to uncover the extent of thalidomide-impaired people's health problems to:

- Raise awareness of the views and experiences of thalidomide-impaired people
- Inform health professionals about their needs
- Improve the quality of information available to thalidomide-impaired people
- Improve thalidomide-impaired people's quality of life.

Methodology

The research was designed to ask questions that thalidomide-impaired people themselves had defined as important. So, throughout the research, the project team aimed to involve thalidomide-impaired people in conducting the research.

The research originally consisted of four stages, with each task informing the next:

- A review to find out what previous research has been done on this subject
- Focus groups to identify issues that thalidomide-impaired people consider important, carried out at the 1999 Thalidomide Society conference
- A structured questionnaire survey administered by telephone
- Depth interviews to explore important issues in further detail.

Following the completion of the research, the project team and Steering Group decided that an additional, fifth stage was required to investigate whether thalidomide-impaired people had experienced greater health deterioration than the general population. In February 2001, the British Market Research Bureau (BMRB) asked a cross-section of the general population, aged 35–44, a number of the same questions as the telephone survey to compare answers.

Key findings

1. Current state of health

Thalidomide-impaired people and a cross section of people from the general population were asked to describe their health and then compare it to that of other people of a similar age. Their answers show that, while most thalidomide-impaired participants would describe their current state of health as either average or good (87%, n = 180), they thought that their health was worse than that of other people of the same age. For example, over a third of thalidomide-impaired participants (43%, n = 90) said that their health was worse than other people the same age, in comparison to 8% (n = 39) of participants from the general population.

Thalidomide-impaired participants have experienced deterioration in health over time, for example, two thirds (65%, n = 134) said that their health was worse than five years ago and three quarters (74%, n = 153) that it was worse than ten years ago. Deterioration over time has been greater among thalidomide-impaired participants than the general population, for example, under a quarter of the general population (22%, n = 94) said that their health was worse than five years ago.

2. Health problems and medical conditions experienced

Over two thirds of participants (68%, n = 143) are reporting an increase in musculo-skeletal conditions such as muscular pain, arthritis, joint pain and general increase in pain and stiffness. They also reported: increasing awareness of internal malformations such as kidney, stomach and gynaecological problems, the deterioration of existing medical conditions, for example, sensory impairments, depression and stress-related symptoms such as fatigue and headaches.

Eight out of ten participants (82%, n = 172) said that they were in pain, with six out of ten (64%, n = 133) saying that they were in moderate to severe pain, and four out of ten (41%, n = 86) reporting being in pain either all or most of the time.

More thalidomide-impaired participants (88%, n = 179) than the general population (11%, n = 49) said that they expected to face either some or a lot of extra problems as they aged due to their impairments. However, they found it difficult to anticipate what those problems might be.

3. Health services

Most participants felt that health services were not fully meeting their needs. For example, seven out of ten participants (72%, n = 150) said that health professionals don't understand the problems and needs of thalidomide-impaired people. Over half (56%, n = 117) said they could not easily access a health professional with expert medical knowledge of the health needs of thalidomide-impaired people. Over half (53%, n = 110) said that health professionals are not aware of their individual health needs.

Participants reported a variety of both good and bad experiences with health professionals. For example, over half (51%, n = 104) felt that health professionals respected their knowledge and expertise about their health needs, while a third (36%, n = 74) did not.

Participants felt that experiences with health professionals were good if they were approachable and accessible, were understanding of, if not always knowledgeable about, thalidomide impairments and related medical conditions, listened and respected their views and worked flexibly with them to find solutions.

Bad experiences with health professionals included: lack of health professional knowledge which resulted in medical errors, being patronised and not listened to, lack of respect for patient views and knowledge and, on occasion, discriminatory attitudes towards people with impairments. Participants said that bad experiences with health professionals discouraged them from using their services.

4. Impact of health problems on life

Participants said that problems with their health and impairments had impacted on every area of their lives. In order of the number of times they were mentioned, areas of life affected were:

- Carrying out day-to-day tasks (73%, n = 151)
- Emotional effects (71%, n= 146)
- Exercise (65%, n = 131)
- Home and family life (62%, n = 126)
- Work or study (60%, n = 87)
- Travelling and getting around (53%, n = 110)
- Social life (51%, n = 105).

Generally, thalidomide-impaired people said that they received financial assistance, help and support from family and friends, used equipment or aids and had adapted homes. Most people neither received nor wanted additional help and support. Some felt that they would benefit from support from home helps or personal assistants, as well as equipment or adaptations to their homes. However, three quarters of participants (75%, n = 153) expected to need more support and equipment in the future.

5. Social services

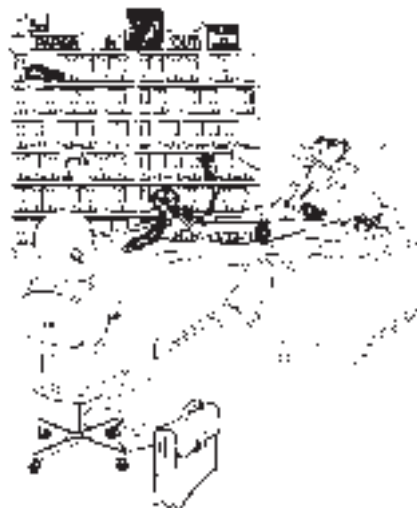
Many participants (approx. 60%) had not approached social services for help. Of those that had, some reported good experiences, saying that they found social services helpful, offering them flexible and prompt services and equipment. However, one third of participants said that they had problems getting the support (40%, n = 81) or equipment (29%, n = 59) they needed. Problems included lack of staff awareness about their needs, inappropriate eligibility criteria, inflexible services, limited resources and long waiting times for assessments and services.



“Just give Social Services a call when you need to come back out and someone from the office will return the ramps.”

6. Employment

Participants said that health problems affected their employment in a variety of ways. They said that work-related tasks caused increasing pain and fatigue which, for some, had led to them either stopping work or reducing their hours. Some participants said that they had not experienced any discrimination from employers or colleagues. Other participants felt that employers were reluctant to employ them and, if they did, were reluctant to supply the aids and adaptations they needed to work.



7. Psychological effects

Participants felt that there had been an emotional/psychological impact of being impaired by Thalidomide because of being treated differently either by their family or other people. They reported:

- Negative feelings towards their impairments
- Wanting to be independent and like everyone else
- Frustration caused by the limitations they faced in daily life.

A few participants said that, as a result, they had experienced periods of depression, while others felt that they had come to terms with their impairments and the limitations they faced in daily life.

Participants, who had undergone counselling, reported mixed experiences. Most said that it was helpful, while three participants made different suggestions for improvement:

- Counselling services should be physically accessible
- There should be specific counselling for people with impairments
- There should be more counsellors with impairments.

8. Information

Participants said that the main, most useful sources of health information were:

- The Thalidomide Society (21%, n = 32)
- The Thalidomide Trust (18%, n = 27)
- Themselves (11%, n = 17)
- Their GP (10%, n = 15)
- Other thalidomide-impaired people (9%, n = 14)
- The Internet (9%, n = 14).

“ Your credentials for the position are impeccable but as you can see it’s company policy to keep all of our stationery on the top shelf. ”

Most participants felt that they would benefit from receiving health information on:

- Specialist health services (54%, n = 124)
- Medical and social benefits (47%, n = 99)
- Aids and equipment (47%, n = 98)
- Local health services (45%, n = 94)
- Patient rights (44%, n = 91)
- Their impairments (43%, n = 89).

Participants wanted specific information on health and social services, such as what services and benefits are available, eligibility criteria and how to access services, thalidomide impairments and related medical conditions and health problems, treatment options and second generational issues.

Participants felt that information should be gathered and available from a central point. Information needs to be accessible through a variety of means such as the Internet, post and by telephone. The Internet is not sufficient on its own as approximately one third of participants have no access to either the Internet (36%, n = 80) or email (39%, n = 86).

9. Participant suggestions

Participants made a number of suggestions for improving their health quality of life. The most popular suggestions were:

- Increase health professional knowledge of thalidomide impairments and related medical conditions and health problems
- Health professional training in disability equality awareness, patient communication and user involvement
- Collation of health information into a central database, disseminated through information networks to health professionals and beneficiaries of the Thalidomide Trust.



***“We’re in luck!
I’ve found all this medical information
concerning cerebral palsy.”***

Conclusion

- Although there has been extensive research about thalidomide, there has been little research on the health and deteriorating health of thalidomide-impaired people. There needs to be further investigation into the health problems thalidomide-impaired people face both now and in the future
- There is evidence that thalidomide-impaired people's health has deteriorated more than that of people of a similar age from the general population
- Health problems have impacted on many areas of thalidomide-impaired people's lives. Many thalidomide-impaired people need more support in daily living and most thalidomide-impaired people are likely to require additional support in the future
- In many cases, impairment has had an impact on people's emotional health. Appropriate 'talking' therapy services, such as disability specific counselling, need to be available to thalidomide-impaired people, if they want it
- The general public is still not generally aware of disability issues and etiquette
- Health and social services are often not meeting thalidomide-impaired people's needs due to lack of knowledge and information. Health and social care professionals should be encouraged to take up training in disability equality awareness issues, patient communication and user involvement
- Information which does exist is not always reaching the 'right' people. More appropriate ways of making information available to health professionals and thalidomide-impaired people need to be developed. Both a formal information collation system, for example a central database or the Internet, and informal information networks between health professionals and thalidomide-impaired people need to be established to improve knowledge and distribution
- Thalidomide-impaired people and health professionals need information about thalidomide impairments and related conditions, medical tests and investigations and the impact of treatments on quality of life
- Due to the relatively small number of thalidomide-impaired people, solutions to problems need to be relevant to people with similar impairments or be low cost to benefit thalidomide-impaired people as an independent group
- The time for action is now given the age of beneficiaries, the current political climate encouraging patient-centred care and before existing medical knowledge is lost, as the medical professionals who investigated thalidomide impairments in the 1960s reach retirement age.

Recommendations

The recommendations from the research have been grouped under seven headings and have been sub-divided into attitude and action suggestions:

1. General awareness

Attitude

- Increased recognition and awareness of the specific and on-going health and social care needs of thalidomide-impaired people
- Recognition that thalidomide-impaired people experience many of the same problems functioning in society as all people with impairments
- Recognition that any solutions to their problems will have a wider impact on individuals, their families and society.

Action

- Removal of obstacles to participation in society by increasing disability awareness and access to public buildings.

2. Health and social care professionals

Attitude

- Recognition that thalidomide-impaired people want help and support that enables them to maintain their independence
- Recognition of the social impact and financial cost of impairments
- Recognition that impairments have a psychological impact on people's emotional well-being
- Improved awareness of the availability of counselling services for people with impairments, for example talking therapies
- Recognition that assessment criteria for services and benefits are sometimes inflexible for people with impairments.

Action

- General training for health and social care professionals in disability awareness
- Specific training in alternative medical tests, investigations, treatment and care for people with limb impairments
- Communication skills training for health and social care professionals to enable them to listen to and involve people with thalidomide impairments and their carers in their own medical care and treatment
- Address health problems, if required, through annual health assessments, including referrals to physical therapy services
- Investigation into the psychological effects of physical impairments
- Automatic offer of referral for needs assessment and occupational therapy to provide appropriate, cost-effective and targeted services and equipment
- More flexible assessment criteria to allow people to be judged on their individual circumstances.

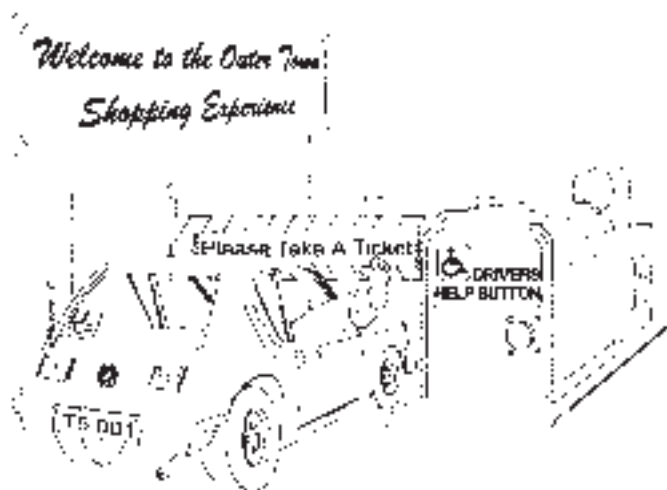
3. Public transport

Attitude

- Recognition that the provision of public transport is variable and needs improvement
- Recognition that public transport officials' attitudes can impede people with impairments from using their services.

Action

- Training and education for public transport officials in disability awareness and etiquette
- Improve and increase facilities for wheelchair users on trains
- Increase the number of adapted buses with lower floors.



4. Employment

Attitude

- Recognition that some employers are discriminating against people with impairments during recruitment and retention
- Recognition that some colleagues' attitudes towards people with impairments can be discriminatory, at least initially.

Action

- General training for employers and employees in disability awareness to increase understanding of and enable them to make full use of employees with impairments
- Greater flexibility of working practices to accommodate all employees' individual circumstances and needs to encourage job satisfaction and increased productivity
- Automatic offer to refer employees with impairments to either an occupational health department or to a disabled employment advisor at the local job centre for assessment.

5. Information

Attitude

- Recognition that people with impairments need more information about their medical condition, benefits, health and social services.

Action

- Dissemination of project information to key health professionals, eg occupational therapists/limb manufacturers/social services/NHS Trusts where there is a high percentage of thalidomide-impaired people/British Society for Rehabilitation Medicine/Disabled Living Centres
- Establish a central information unit/resource through which health information can be shared between health professionals, thalidomide-impaired people, their families and carers

- Information needs to be met through a variety of formats, such as the Internet, email, telephone and post, to ensure equity of access
- Central information unit/resources should contain information on:
 - a) Thalidomide impairments and related medical conditions
 - b) Anonymised case studies of individual health problems
 - c) Equipment, aids and adaptations
 - d) Local self-help groups and other useful national and international organisations
 - e) General health information, such as local services and patient rights
- The central unit/resource should also have a secure site for information-sharing between beneficiaries of the Thalidomide Trust
- Information on health issues should be kept up-to-date
- Production of information leaflet with details of:
 - a) Useful organisations such as NHS Direct, benefits advice line and disability rights organisations
 - b) Medical tests and investigations
 - c) How to access health specialists
 - d) How to access other useful health and social care services
 - e) Rights to health and social care services
- Information leaflet for occupational therapists setting out the problems thalidomide-impaired people face in daily living.

6. The Thalidomide Society

Action

- Thalidomide Society to disseminate and take forward research
- Use information technology to highlight key issues and generate discussion among its members
- Increased co-operative working and information-sharing with international thalidomide societies for mutual benefit
- Continued provision of informal support networks for thalidomide-impaired people
- Continued support of local services through the provision of information and networks.

7. The future

Attitude

- Recognition that thalidomide-impaired people's health needs are changing over time and may require medical assessment on an on-going basis to predict future health needs.

Action

- On-going monitoring and evaluation of thalidomide-impaired people's health and the impact of the research's recommendations.