



The Independence

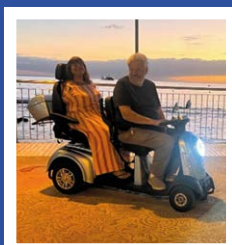
Winter 2025

The Thalidomide Society Newsletter



See inside

Page 4 Read about
Mandy's holiday
recommendation



Page 10 Lottery results

Page 11 Personal Support – Maintaining your
Dignity and Independence Zoom
meeting with Neil Spooner



Welcome to our newsletter!



I hope you enjoyed the summer and are gearing up for the festive season. The Society has been busy over the last few months, especially with our Personal Support Project. We have received such positive feedback and are excited to continue moving forward. Please keep an eye out for our upcoming Zoom meetings featuring expert speakers.

We are looking forward to our Annual General Meeting/Conference in April 2026, being held at Burleigh Court, and are excited to tell you that Neil Spooner will be our main speaker. Further details will follow soon about our weekend.

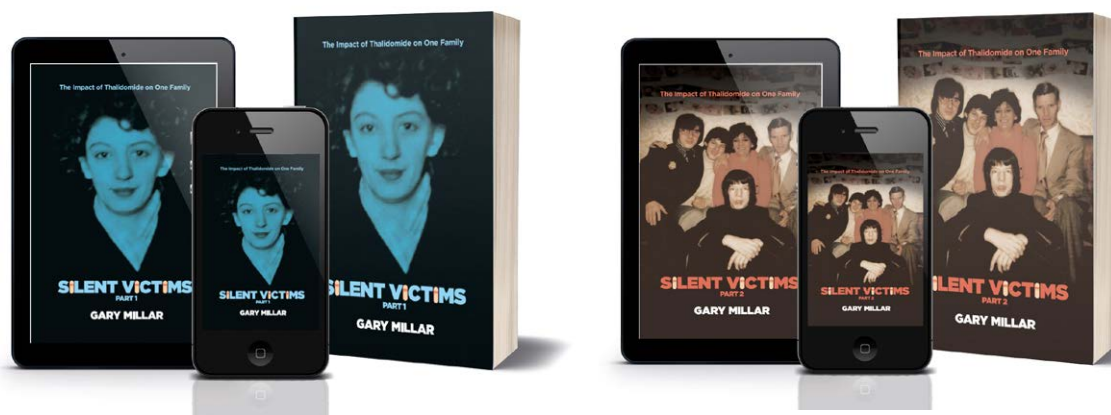
If you have anything of interest you would like to share with others, please

contact Heather at heather@thalidomidesociety.org

On behalf of the Board of Trustees, I wish you a very happy Christmas and look forward to an exciting and productive 2026.

Mandy De La Mare – Chair

Silent Victims: Parts 1 and 2 The Impact of Thalidomide on One Family



The eldest brother of Thalidomide survivor Leslie Millar has written two gripping books about the devastating impact of Thalidomide.

In *Silent Victims: Part 1*, Gary Millar, former Lord Mayor of Liverpool, focuses on the life of Margaret Marjorie Millar – Madge – mother lost in the fog of the drug's tragic legacy. Told through meticulously transcribed medical case notes and interwoven with deeply personal reflections from Madge's son, Gary, *Silent Victims* offers a raw yet factual exploration

of Thalidomide's impact through the lens of one family and is a call to reflect on the untold stories of all of the silent victims of the Thalidomide scandal.

On November 24th, his publisher, Writing on the Wall, launched *Silent Victims: Part 2*, the powerful sequel to his acclaimed *Silent*

Victims: Part 1. This compelling follow-up shifts the focus from Gary's mother, Margaret, to the wider Millar family, tracing six decades of resilience, love, and struggle in the aftermath of Thalidomide.

At the heart of the story is Gary's brother, Leslie Millar, a Thalidomide survivor whose life was shaped by a world that often misunderstood and excluded him. Through photographs, memories, and meticulous research, Gary reveals the profound impact of Thalidomide, not only on Leslie, but on his entire family.

Raw, honest, and ultimately hopeful, *Silent Victims: Part 2* gives a voice to the silent victims of medical negligence, while celebrating the strength, humour, and humanity of those who refused to be defined by tragedy.

Drawing on photographs, memories, and painstaking research, Gary uncovers how the shadow of Thalidomide shaped not only Leslie's life, but also the lives of his parents and siblings who lived in its aftermath.

Read the stories, and discover a moving narrative of heartache, courage and resilience.

Get your copies

Silent Victims: Part 1 is available at writingonthewall.org.uk/shop/silent-victims/

Silent Victims: Part 2 is available at writingonthewall.org.uk/shop/silent-victims-part-2/

Gary Millar FJMU

www.instagram.com/garymillaruk
www.linkedin.com/in/garymillar/

Reviews

Former BBC Merseyside presenter and journalist Linda McDermott says: *"Chomping at the bit to read Silent Victims Part Two. Astonishing story, lovingly, faithfully and beautifully crafted. Love, devotion, bravery, institutional failings, resilience, fortitude, even humour, amidst the most dire of circumstances. Part One and Two should be up for Book of the Year."*

Thalidomide survivor Mandy Hendrie said: *"Hey you should hold your head up so high you have done an amazing piece of work you have probably done what so many other siblings wished they could have put into words of the actual damage it done to everyone in the family not just the victims of the drug and I personally want to thank you for your articulation and sensitivity all the way through the first book and without this second book which I can not wait to read (already ordered) !!! And I am 100% sure it will be as honest and thorough as the first."*

Former Director of the Thalidomide Trust, Dr. Martin Johnson said: *"Gary shows how powerful the impact can be on a brother or sister of having a sibling with a severe disability. Thalidomide damaged not only the child directly affected, but always the whole family. I commend this book for bringing this situation into the public eye and from the writer's heart."*



Scan QR code to get to Gary's social accounts.

Holiday with less barriers:

Tenerife's accessible gem

The Mar Y Sol complex is an accessible spa hotel located in Los Cristianos on Tenerife with authentic Spanish-style architecture. The hotel has its own diving school and the whole complex has been built to be fully accessible. It is however, important to note that the hotel is positioned on a hill.

The restaurant is truly spacious, equipped with a pool bar, offering you a varied buffet. Food ranges from typical Canary/Spanish to international cuisine. In addition to chef's specials, guests can enjoy gastronomic themed evenings. Special diets or vegetarian menus are available on request. The staff will happily assist those guests who have difficulties serving themselves from the buffet. In accordance with Spanish legislation, the whole restaurant is a non-smoking area.

The pool area is one of the favourite places frequented by guests and includes two big pools and a therapy pool. One of the big pools (10.80 metres x 16.80 metres) is heated all year round to approximately 32°C and provides neck showers, whirlpools, water cascades, jacuzzis, and massage showers. The second big pool (10.60 m x 14.60 m) has a depth rising from 1.10 m to 2 m and a water temperature that is kept between approximately 22°C and 25°C. Both main pools are equipped with a

hoist and easy-to-use steps with handrails to help the elderly and the disabled gain access to the pool.

The therapy pool (5.70 m x 10.70 m) has a depth rising from 50 centimetres to 90 centimetres and is equipped with handrails along one side for the purpose of walking therapy. There is also a ramp into the therapy pool for wheeled access. The water temperature in this pool is also kept between approximately 22°C and 25°C.

For comfort, the pool area is equipped with many sunbeds. Their height allows wheelchair users to transfer onto the sunbeds with ease, and the large sunshades and palm trees offer shelter from the sun. The pool area is also provided with a non-smoking area. A lifeguard supervises the pool eight hours a day to ensure the safety of all swimming pool users.

Mobility equipment

There are diverse types of shower chairs for use in the roll-in showers. These do need to be pre-booked at the time of booking and are free of charge; there is the choice of a static chair, a shower chair on four small wheels, and a self-propelled shower chair.



Room specifications

The hotel has six different room types and categories. All accommodation units are equipped with an emergency telephone and use of the flat-screen TV. There is a safe in each room, and a lock can be obtained from reception at a charge, which is refunded when you check out.

All superior studios, superior apartments, comfort rooms, and premium apartments, as well as their balconies and patios, are non-smoking areas.

Each type of accommodation has a kitchen with cooking plates and a large fridge, an accessible bathroom, and some have elevated toilets with grips. Also supplied are hair dryers and a wheeled trolley container for bathroom accessories.

The available rooms are as follows:

Studio Superior

Modern single-room accommodation.
Balcony with garden table and chairs.

Standard Studio

Economy single-room accommodation.
Balcony with garden table and chairs.

Comfort Room

Equipped like a typical hotel room this is a comfortable one-room accommodation.
Balcony with garden table and chairs.

Standard Apartment

Two-room accommodation with separated living and bedroom area, accessible bathroom and balcony or patio.

Apartment Premium

Modern, spacious apartment with two accommodation areas. Living-room, a separated bedroom, a large bathroom, and some have a large balcony-patio.

Apartment Superior

Modern, spacious two-room accommodation with living and bedroom area, large bathroom and balcony or patio.

To find out more about the rooms and the hotel visit www.marysol.org/

Facilities

- ▶ Adapted and wheelchair-accessible transfers or car hire included.
- ▶ Equipment hire.
- ▶ Modern therapy centre with a variety of individually tailored holistic and traditional treatments.
- ▶ Appliances for hire (electric beds, hoists, air mattresses, electric wheelchairs, etc.).
- ▶ 24 hour emergency service.
- ▶ Excursions for everybody.
- ▶ Golf & diving for everybody.
- ▶ Accessible sports hall (530 m²).
- ▶ Bedroom and bathroom door width 80 cms.
- ▶ Bed height 50 cms.
- ▶ Toilet height 41 cms.

The above information is about the hotel I have been to two years running and thoroughly enjoyed myself. It was my friend Geraldine that introduced me to it, she has been visiting this complex for over 30 years and I can completely understand why she goes there.

Geraldine, Jackie, and myself have just returned from Mar Y Sol. Geraldine and her



partner, along with me and my partner, all flew from Bristol Airport. We were extremely impressed with Bristol's disabled assistance; they were efficient in getting us onto the aircraft without too much stress. However, when we got on the plane there was a bit of a kerfuffle. This was because when Geraldine's partner booked the seats, he didn't realise that one of them would be near the exit on the front row. To top it all off my partner and I inadvertently sat on Geraldine's allocated seat, but to be honest, even if I had sat on my allocated seat on the plane, I too would have been told that I couldn't sit there due to the exit. The air hostess could have handled the situation better, but the outcome was that the assistance had to come back on and transfer Geraldine into another seat, which is embarrassing when the plane is full of people.

The journey to Tenerife was fine, although when we got to Tenerife Airport everybody was stuck on the plane for

nearly an hour because the stairs for the plane were broken and they had to find a working set. Once the walking passengers were off, we had to wait for the lift to get us off the plane; by this time we were well over an hour since landing. Once the assistance arrived, they were good and helped us through the airport and to get an accessible taxi for Geraldine and a normal one for myself.

It was quite late when we arrived at Mar Y Sol, and by the time we booked in and threw everything into our rooms we were ready to go out to eat. To be honest, the food in Mar Y Sol is not the best; breakfast is not too bad, and lunch is okay, but for anything else we go out. Most of the restaurants and bars along the front and up the hill from Mar Y Sol are accessible for wheelchairs.

Geraldine had booked a standard apartment for me and my partner and herself and her partner; for Jacqueline she booked a standard studio apartment. The rooms are lovely, spacious, and perfectly adequate. It is good having accessible bathrooms that are spacious; I have never

had such a big bathroom in England like you do there.

We spent every day by the pool on the sunbeds. They are difficult to get out of due to the fact that they are sagging in the middle, and if you haven't got arms to push yourself out of them, you have to be pushed or pulled out. However, we did not let that deter us, and we were certainly on them every day, and we made full use of the large parasols.

We went swimming every day in the pool and thoroughly enjoyed it, especially the water features when they were turned on. Because everybody here has a disability, you don't have people watching when you're getting in or out of the pool, especially if you must use the hoist. The stairs into the pool for me were great, and once I had counted the number of steps I was okay. The pool has a lovely ledge where us three girls like to sit and put the world to rights; our partners said that we looked like the three witches sitting there planning!



The hotel is on a fairly steep hill, and we call it the cardiac arrest hill, I must confess I cheat, as my partner and I hire a mobility scooter for two. It makes life so much easier, as it saves my partner guiding me through crowds, and it is the closest I am going to get to being a passenger on a motorbike. Last year when we went, Geraldine's partner pre-booked the mobility scooter for us, but this year my partner booked it on arrival. It took just a few hours to arrive and for 10 days hire it cost €250, we did not think that was too bad.

We took advantage of their holistic treatment area and we had two massages each. Because the therapists are so used to dealing with different physical problems, they are all good and will also help you dress and undress.

We love the entertainment at the restaurants and bars and we particularly like Charlie's bar, which has a tribute act to Elvis and Rod Stewart. Some of the staff were still the same as last year and remembered us, and so did Elvis (Simon King). We also went to see a band that Geraldine and her partner have been following



for seven years in Tenerife, and yes, you have guessed it, they also recognised us, I wonder why!

At the end of our stay the hotel helped us book our taxi back to the airport. The assistance at Tenerife Airport was good, the only criticism we would have with assistance is that it would be so much nicer for those that have to transfer from the aisle chair to an aeroplane seat could board first as it isn't the most dignified procedure to perform in front of an audience. However, they got us onto the plane and when we arrived at Bristol Airport we didn't have to wait too long for assistance to get us off the plane. Because they were so busy, we had to make our own way through arrivals

without assistance, we did okay but it would have been easier for my partner, who has to guide me and haul the luggage. Geraldine's partner managed to find a trolley and take our luggage so that my partner was able to guide me through the crowds.

We all had a fantastic holiday and we would highly recommend Mar Y Sol as it is totally accessible and we do not feel like we stand out there. It is a practical hotel for disabled people so bear that in mind and do not expect five-star accommodation. Also, you do have to be understanding of other guests who may have a range of disabilities and different social behaviours.

Mandy de la Mare

Winter 2025 **7**

Your questions and answers in our Facebook community



We have picked out a question from our Facebook page and reproduced here that some of our readers may find useful.



I have just done my pension forecast for February, when I reach 66, and found that this works out to be much less than my current Employment and Support Allowance (ESA). In fact, I will be £50 a week worse off.

Now, I'm assuming all my ESA will stop at 66 (pension age) and be replaced by my pension. For those who have already reached 66 and taken their pensions, and were perhaps on ESA can you shed any light on this, please?

I'm just assuming at this point that the employment benefit (ESA) stops at pension age and your pension kicks in to replace it. I haven't spoken to the Department for Work and Pensions (DWP) yet, but I thought I'd ask others about their experiences first. It's quite a shock to find that, over a four-week period, my income will drop by £200!

Others may wish to check them out. It's really simple to do online through the government gateway, using your driving licence and passport as ID. I just googled "DWP Pension Forecast," and up came the Gateway Site. I clicked on it and followed the really clear instructions.

Most of my working life has been spent at home with children, claiming child benefit and getting NI credits, or being unable to work and on work-related benefits – again, getting your full NI contribution paid.

I had to give up work in my late 20s due to problems with my neck and back, which meant an office job was too sedentary for me. Then, with an 11-year gap and another two little ones, I didn't manage to get back to work before my husband retired on ill health and got his full occupational pension. We needed a complete change for him and moved abroad for around 12 years, where the younger ones were educated. Being in the European Union, this didn't affect my benefits, as they were considered "exportable."

Interestingly, if you ask Google the basic state pension rate, it gives it as £176.45 per week, yet mine is £230.25. So, where and why do I get the extra? There are no explanations – just figures.

Do have a look, even if you have a couple of years to go, as it's unlikely to change much now.

Replies

Facing the state pension: a community's experience

For many people who have relied on work-related benefits, reaching state pension age can bring an unexpected financial shock. A recent community discussion on the Thalidomide Society Facebook page highlighted the challenges of transitioning from Employment and Support Allowance (ESA) to the state pension and the impact it can have on household income.

Understanding the state pension

The amount someone receives depends when they reached state pension age:

- ▶ **Before April 2016 (old state pension):** Up to £176.45 per week
- ▶ **After April 2016 new state pension):** Up to £230.25 per week

To qualify for the full new rate, 35 years of National Insurance contributions are required. Most people retiring now fall into the post-2016 category, but even then, the pension often doesn't match the support people were used to receiving through ESA.

The ESA transition

ESA, a taxable benefit designed for those of working age who cannot work, stops when you reach state pension age. Other benefits, like Personal Independence Payment (PIP), continue unaffected. Importantly, claimants must inform the Department for Work and Pensions (DWP) when they start receiving their state pension, as ESA doesn't always stop automatically.

The financial impact

For some, the loss of ESA means a drop of nearly £5,000 a year. Those without private or occupational pensions feel the difference most sharply. Even within couples, individual income reductions can be significant, highlighting the personal strain that retirement can bring.

Life stories behind the numbers

Many in the community shared how their lives, balancing careers, family, and disability, have found it difficult to build pensions. Some had to focus on raising children, while others managed full-time work with limited options. These experiences have left long-term gaps in retirement

income, something that was highlighted in a 2016 study on loss of earnings among people affected by Thalidomide, though little has changed since then.

Looking ahead

Some are exploring the option of deferring their state pension to continue receiving ESA for a while longer or relying on private pensions taken early on health grounds. However, the reality is clear: for many, careful planning is now essential to avoid unexpected financial strain.

Key Takeaways

- ▶ Transitioning from ESA to state pension can lead to a substantial loss of income.
- ▶ Deferring state pension may be an option in some cases.
- ▶ Historic barriers to work and pension building continue to affect income for many retirees.
- ▶ Raising awareness and planning ahead can help soften the impact of these changes.

For those approaching retirement, the lesson is simple: understanding your benefits and planning ahead is more important than ever.

The Thalidomide Society Lottery – recent draw results

Below are the winning numbers from our recent lottery draws. Congratulations to all our winners, and thank you to everyone who continues to support the Society through their participation.

Latest draw results and winning numbers

► Friday, 7 November 2025
Numbers: 0, 1, 5, 3, 6, 7

► Friday, 31 October 2025
Numbers: 2, 2, 5, 3, 9, 8

► Friday, 26 October 2025
Numbers: 8, 6, 3, 7, 5, 5

► Friday, 17 October 2025
Numbers: 4, 8, 9, 4, 9, 3

► Friday, 10 October 2025
Numbers: 8, 9, 0, 0, 3, 5

Congratulations to Arbory Farnworth, who won five bonus entries in the next draw.

► Friday, 26 September 2025
Numbers: 5, 5, 7, 3, 6, 1

Congratulations to Simone Illger, winner of £25, and to Jean O'Hare, who won five bonus entries in the next draw.

► Friday, 19 September 2025
Numbers: 9, 8, 3, 3, 8, 2

A message of thanks

We're grateful to Marie Pearse, who leads The Thalidomide Society Lottery. Marie shares this message: "Thank you to everyone who has supported our lottery. We hope you will continue to take part, and we warmly welcome new supporters. Funds raised help us deliver important projects, including our *Oral History Project*, which continues to be invaluable in recording and preserving our shared history."

Support, join, and play

A minimum of 50% of the total

lottery proceeds are spent on supporting the work carried out by The Thalidomide Society, 18.4% on prizes, and 31.6% on the running cost and administration of the lottery.

So why not join? Anyone can play, members, families and friends at www.unitylottery.co.uk. T&C's 16 years & over, resident in GB apply. www.thalidomidesociety.org

You could win up to £25,000! Odds of winning a prize: 1 in 63. Remember: you have to be in it to win it! For a detailed breakdown of the odds and prizes, see the lottery rules (www.unitylottery.co.uk/rules/) and the prizes (www.unitylottery.co.uk/prizes/).

**Promoter: Marie Pearse
(Member & Promoter)**

The logo for the Unity Lottery, featuring the word "unity" in a bold, red, lowercase sans-serif font. The letter "i" is stylized with a red dot above it.

Play now... www.unitylottery.co.uk/causes/the-thalidomide-society/

Direct Payments explained



Neil Spooner, Zoom meeting

On Tuesday, the 25th November we held our second Zoom meeting relating to our project. Personal Support – Maintaining Our Dignity & Independence.

Our speaker on the day was Neil Spooner, who is an independent living advisor, who spoke to us about funding personal assistants and the different ways this can be done.

Neil asked those attending who uses Direct Payments and their experiences of it; overall, the feedback was good, with most people having a good experience.

What is a Direct Payment?

This first came about in 1996 with the Community Care Act, with the first payments, known as Direct Payments, being paid from local authorities in 1997.

People applying for support must first have an assessment by a social worker, although it can be done via the NHS. If you believe you need

support, your first point of contact is adult social care. Following the assessment, this can result in a payment being offered. This is usually a direct payment, and the individual will buy in their own care, which is usually a personal assistant; this means the individual becomes an employer. It should also be noted that the better the social worker knows you, the better the assessment. When the assessment takes place, it is advisable to have a family member or friend with you who can offer support.

It is interesting to know that the figures from the Department for Work and Pensions say that there are 16.8 million disabled people in the UK. However, only 118 thousand people are receiving a Direct Payment.

Direct Payments can be used to employ a personal assistant or buy in day services. If you require other support, it is important to build a relationship with your social worker and ask.

You may be asked to contribute to your payment; however, your first £23,250 is not counted, and it is also important to remember that if you are a beneficiary, any trust money cannot be taken into account.

When you decide to employ a personal assistant, you are not allowed to employ a person who lives in your home with you.

As an employer, you issue a contract and manage the funding yourself; however, you can opt for a managed account, and this is managed by adult social care. Many people enjoy managing their own account.

Presently it is not easy to get staff, and if you employ a PA who isn't right, it is important to abide by the appropriate procedures to terminate employment.



Therefore, insurance is essential; companies such as Mark Bates Ltd are often recommended by Adult Social



Care. The majority of PAs are female; you can, however, ask for a male, particularly when it comes to personal care. This is applied for via the Equalities Act 2010.

Using Direct Payments gives you control and choice, which is very important. Neil Spooner is happy to help and answer any questions you may have.



Maintaining Our Dignity & Independence

WHAT MAKES A GOOD PERSONAL ASSISTANT?

The next online meeting
will take place in
February 2026

More details coming soon.....



 Thalidomide Society
Est. 1962

Contact: 07894 599187 Email: Neil.Spooner@peopleplus.co.uk

Do you have a story, tip, or anything else of interest to share with other members? We are always on the lookout for features from

members for the newsletter; please do get in touch with Heather by email at heather@thalidomidesociety.org.

The Thalidomide Society, The Old Doctors House, 74 Grange Road, Dudley, West Midlands, DY1 2AW.

www.thalidomidesociety.org
info@thalidomidesociety.org

The Thalidomide Society is a charitable incorporated organisation. Registered Charity in England and Wales (No. 231708).

Julie Dixon, Operations Manager
julie@thalidomidesociety.org
07802 604 205

Heather Trueman, Assistant Administrator
heather@thalidomidesociety.org
07933 121 300

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