

Welcome to the Newsletter

Carolyn Desforges and Sue Gooding, Editors



Spring is a time for new beginnings and, of course, the Spring NAC Newsletter! This edition contains feedback from the Trauma and Self-Care webinar, some insights into inflation (how it is measured and what this means for us), and how the Future Care Costs research project was conducted and reported. We introduce our new NAC member David Alexander, and let you know about a new Meetup group for those beneficiaries who have a visual impairment. Any feedback and indeed any offers of contributions for the next Newsletter would be greatly appreciated, please email editor@ttnac.org.

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Latest News from the Chair

Rowland Bareham, Chair of the NAC

As I started to write, I reflected that it's April, meaning that the first quarter of 2022 has whizzed by – how time flies! Christmas didn't seem that long ago.

So much has happened in the last quarter: we've had the Earlier, Great and Longer Report (see Graham's article within); the results of the Beneficiary Consultation for the Diageo Review, leading to the firming up of our 'Asks' for the review talks (for which I appreciate some of the messages of support and thanks); NAC colleagues have been busy recruiting our new Communications Officer. Paul Randall started working with us on 19th April - "Welcome Paul"! More introductions in our summer edition; The NAC, together with Trust staff and trustees have also begun work on the Trust's strategic plan for the next 5 years (1 October 2022 – 30 September 2027). We will be reporting on this as work continues over the year.

We've had the outcome of the NAC election process with fewer candidates than places. I thank those leaving the NAC, Maggie Boyd and Phil Williams, for all they've done. And I welcome on board David Alexander joining the NAC.

Since the conclusion of the NAC election process, Sue Gooding has decided to resign from the NAC from 19 May. I thank Sue also for all she has done.

Until next time, take care.

Committee Highlights: Health & Wellbeing Understanding Trauma and Self-Care Webinar

Carolyn Desforges NAC Health & Wellbeing Co-Chair Listens in...

Bonita Ackerman Du Perez, a master therapist specialising in trauma, anxiety and stress management, led an informative webinar on 14 February 2022. Her focus was on trauma, how to manage its effects and the neuroscience behind it. This has been recorded and is on the Thalidomide trust website should you wish to watch it back:

<https://www.thalidomidetrust.org/could-you-benefit-from-emdr/>

Our mind/brain is an individual muscle that needs care, attention and feeding. It is normal for our mental health to fluctuate – we can thrive, feel okay, struggle, and be ill, all within one day. Self-care, early identification, and awareness can help us manage much better.

Everyone has some feelings of anxiety and stress. Some people face this due to past trauma. Most cases can identify a trigger – we all have fight, flight, and a fear/freeze response. We are all individuals – people react very differently as our brains are individual. When our flight and fight reaction is too much for our bodies, or our coping strategies fail, we experience anxiety, stress and trauma. It is common to feel overwhelmed about something that has happened in life. The good news is that with support, this can be managed. Therapy is aimed at supporting a positive change in thinking, behaviour and reactions to the traumatic events a person has experienced.

Our brain is super-efficient and is a pattern-making machine. Like a computer, it downloads programmes to the hard drive (ie. anything that's done repeatedly), it recognises the neural pattern as a new programme and copies and downloads it. The more we use this programme, the more updates it runs and it becomes hardwired. Sometimes programmes are not that effective and they develop bugs.



Anxiety is much the same, when we have anxious thoughts, it creates a neural pathway in the brain, the more we have these thoughts, the stronger they become, until the point that we feel we have no control over them. Thus, unprocessed trauma responses can be held in the brain, disrupting lives, causing a type of self-sabotage. Reactions such as stress, anxiety, high blood pressure, disrupted breathing, heart palpitations, colds etc.

all demonstrate that the body is telling something is wrong and makes it really hard to keep up the routine of our daily lives.

How to identify and stop patterns of thinking

Latest research in neuroscience shows that:

- The brain is more pliable than once believed
- We can change even the most hardwired patterns
- This can be achieved much faster than previously thought

Our brain is changing, with every experience and every conversation. We are creating new neural pathways and new connections in our brains. When we identify triggers to our anxiety, some triggers are obvious, others are not. Our brain sources information based on the emotional response we have, and the association we have made from it. This is often stored in our long-term memory especially if it has been perceived as danger. It is only interested in the fear that was created at the time.

For example, if we had a bee sting as a child, we may not remember the event, but the trigger becomes the buzzing sound. Our senses have a lot to do with triggers – aftershave, door opening, footsteps etc. When you take time to spot the triggers, it's important to decide what is relevant for you.

To get yourself out of an anxious state, ask yourself the following questions:

1. Where am I?
2. What am I doing?
3. What am I thinking?
4. How do I feel?

It may be hard to manage this on your own, and the first step is often seeking help / support. The important thing is that over time the effects of trauma can be managed.

Committee Highlights: Finance - Inflation and You

Phil Williams - NAC Finance Committee Chair until April 22

Many of us have forgotten about inflation, but in the 1970s it was rampant and peaked at just over 25% per annum. This is not to worry you but rather to remind everyone there has been rising and high inflation before.

Inflation is the term used to describe the increase in prices over time.

There are many different measures of inflation but here, I am looking at three in particular; the Retail Prices Index (RPI), the Consumer Prices Index (CPI) and the Consumer Prices Index with Housing Costs (CPIH). These are all different so, for example, last month RPI was 8.2%, CPI was 6.2% and CPIH was 5.5%.



RPI is statistically flawed and regarded to overstate inflation - it is now a national statistic rather than an official inflation measure, though the government still uses it for several purposes. Last year, the Chancellor announced plans to bring RPI into line with CPIH by 2030.

But RPI is very important to beneficiaries as the annual payments from Diageo and the Annual Grants (AG) each April go up in line with this inflation measure – calculated by comparing the RPI in the preceding September with the position 12 months previously. Very unusually, inflation has risen rapidly in the 6 months between October and April.

The inflation rates are calculated by looking at a basket of goods and services. These create an 'average' as it were. At the March Finance Committee meeting, I pointed out that the rising energy costs will have a significant disproportionate impact on many beneficiaries who might be at home more often in the day, wear nothing on their feet and also find excessive layers on their upper body restrictive. Several beneficiaries also have physiological issues controlling their body temperature. This point will be made to Diageo in the current discussions.

The Health Grant (HG) was very unusual in that, when it was established, the funding allocated each year was increased by an inflation measure called the GDP deflator. As we know, in England the Chancellor has confirmed that the HG will be payable for life rather than for the next ten years, with a review every four years. This inflation measure will be changing to CPIH for the first four-year period, but we will have the opportunity at the first four-yearly review to discuss alternative inflation measures. This year, the four UK Health

Departments agreed an 8% increase in the HG to reflect your increasing health and wellbeing needs.

Please do remember to use or draw your Health Grant as soon as possible after 1 June, as this is intended for your use only and does not pass on to your family or estate if you pass away!

If you have any questions, contact me, or members of the NAC or Trust Finance Team.

Phil Williams 07554 016303 phil@philipdavidwilliams.co.uk

In Focus - Earlier, Greater, Longer: Report From the Trust's Future Care Costs Project

Graham Kelly - NAC Research Committee Member

In the March Directors' Update, you were advised that a short report of the long-running Current & Future Care Costs project had been published and was available on the Trust website (with a printed copy available on request). This project investigated the additional needs that Thalidomiders have and will increasingly have in the future, and to estimate associated costs.



The original idea for the project came from the NAC, but it was carried out by Trust staff with the help of specialist experts. The aim was to obtain clear and robust evidence to show to Diageo and the governments that fund the Health Grant, demonstrating that our needs, and associated costs, will increase as we age, and consequently more funding will be needed.

The evidence we put together came from two sources, and all data was treated with strict confidentiality. Firstly, with the help of an expert statistician the study used data from the Holistic Needs Assessments (HNAs) that most beneficiaries have with a member of staff from the Trust. So, thank you, to everyone who has had a HNA, because you made and continue to make an important contribution. Secondly, from 16 "exemplar" cases in which volunteer beneficiaries were assessed in great detail to identify the current and future needs. I'd like to say a massive thank you to the 16 for volunteering to do this.

These 16 were chosen to make sure they represented the full range of impairments across our beneficiary community. In other words, whatever your particular thalidomide-caused impairments, at least one of the 16 had similar impairments to yourself.

The 16 assessments were carried out by Bush & Co, one of the UK's leading Assessors and Expert Witnesses in personal injury cases. They identified the support that those 16 beneficiaries would need and estimated the likely costs - now and in the future. For example, if somebody has 8 hours of care per week now, they may need 20+ hours per week in 10 years' time.

Bush & Co's financial figures were cross-referenced with data from HNAs to create a set of realistic assumptions and the resulting figures were then rigorously reviewed by Hugh Gregory, a Forensic Accountant, to make sure they were robust and to create a model showing how the costs could be applied across the whole beneficiary community. Hugh is a leading name in this field and has been responsible for calculating personal injury costs in many famous cases, such as the compensation payments for the Birmingham Six.

The assessment was comprehensive. On top of social care needs, it considered the cost of things like transport, holidays, pet care, household decoration, home adaptations, entertainment, health treatments and pretty much everything that we pay money for.

What will now happen with the report?

The information obtained from this study has given the Trust a much clearer understanding of the current and future needs across our beneficiary community although, at this stage the future costs are very much best estimates. There is currently a high degree of uncertainty, and the current figures are based on judgements about how quickly the needs of beneficiaries will change over time and the rate at which different costs will increase. However, very importantly, the study has given us a "model" by which we can estimate the cost of meeting those needs. As we continue to gather evidence from future HNAs and have a clearer picture of the likely future cost of things like treatment and care, we can re-run the model to make sure we are always on top of your changing needs and costs.

Prior to having this any estimation of needs and costs was largely guess-work, but now we have a sophisticated model that can be built on and improved in the future. This will be valuable when we talk to our funders because they will see that we have a solid justification for money we ask for in the future.

The report can be found on the Trust website, using this link:

<https://www.thalidomidetrust.org/wp-content/uploads/2022/03/Earlier-Greater-and-Longer-FINAL.pdf>

Our Stories: Introducing David

David Alexander - New NAC Member

We are welcoming David to the NAC this month, April 2022. He is 60 and was brought up in Lanarkshire in the west of Scotland. However, for the last 30 plus years he has lived in Alloa, the main town in Scotland's smallest county – Clackmannanshire. And yes, that is a real place! He has been married for 32 years and has one son who is 23.

This is his perfect weekend...

TV night in or night on the town? I'm happy with either but maybe on balance TV night in

Take away or eating out? I like to eat out



Action movie or historical drama? Action movie

Who or what is your screensaver? On my laptop, I have a picture of our favourite holiday spot in Cyprus. On my phone its my lovely wife

Early bird or night owl? If there is football on the TV - night owl

Whisky or Wine? Neither - Maybe I'm not a **real** Scot I know as I don't like Whisky! I would choose beer or rum

Rugby or Football? Football. My football team is a small team in the lower leagues in Scotland called Albion Rovers. They were my local team growing up

What's your signature dish? - I do a mean mac'n'cheese and I also do a nice steak

I couldn't get through the weekend without... the football

And for those longer breaks – Staycation or travelling abroad? Travelling abroad

Our Stories: Seeing the Wood and the Trees

Geoff Spink NAC Member

Like so many of us, I was born with extremely short arms and few fingers. That single pill that my mother took, also worked its "magic" on my sensory system: I was born with a cyst in place of my right eye and my left eye is affected by nystagmus and coloboma. In short, I have what is referred to as 6x60 vision: what most folks see at 60 metres, I can see from only 6m away. Driving, much to my chagrin, has never been an option, even though I am a diehard petrolhead.



Why am I telling you all this? Because I'm not alone, although there aren't that many of us out there. Living with a physical and a sensory impairment actually adds up to a whole new set of challenges: I not only have the fear of falling, I'm also much less likely to see something on the ground and therefore trip over it. As I get older, I am less and less inclined to walk around in an unfamiliar environment without someone next to me. People at home have to be careful not to leave things on the floor or on the stairs because the chances are I just won't see them.



With age comes a delightful new problem in the form of a cataract. It was identified by Moorfields Eye Hospital some time ago, but if I don't have this treated, I will lose what little vision I have. The consultant ophthalmologist is obviously reluctant to do what is usually a routine operation because if anything went wrong, I would be left completely sightless.

Together with my good friend and fellow Society trustee, Mandy De La Mare, we decided to float the idea of a Meetup group so that those of us who have both physical and vision challenges, could swap ideas and talk about what we might need from the Trust now, and in the future.

The first few meetings have been of three or four of us coming together to talk about how living with impaired vision and thalidomide physical disabilities affects their everyday lives. What kind of apps do you use on your phone? What other aids and adaptations are helpful? What is being researched that we might tap into? Do our Trust staff know enough about impaired vision to give us the support that we so obviously need? Is it safe to go ahead with that cataract op?



We would really like more people to join the group and – between Meetups – to pop into our WhatsApp group which you can join using this link:

<https://chat.whatsapp.com/FJGCaiclYqXD4SASXabmjZ>

It's really important that those of us who do have this set of challenges are there to support each other and to help our brilliant Trust staff to understand our needs better.

To contact Geoff about this or any other NAC matter, email geoff@ttnac.org or call him on **07711 898787**

About the NAC

The NAC is the user-led group that exists to represent the beneficiaries of the Thalidomide Trust by working in partnership with the trustees and staff.

Get in touch

We'd love to hear from you and include your stories and questions in the next newsletter in July. Email feedback@ttnac.org if you'd like to write an article, suggest a topic or ask a question.

If you're on Facebook, look out for the NAC group on www.facebook.com/groups/ttnac