

## Welcome to the Newsletter

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Carolyn Desforges, Sue Gooding and Maggie Boyd, Newsletter Editors



Happy new year! Welcome to the NAC's first newsletter of 2022. We hope this finds you well and enjoying life as the days get gradually lighter and warmer.

In this newsletter, there's an update on exciting new research on measuring blood pressure; advice for dealing with ongoing pain (something experienced by more than 90% of beneficiaries); a focus on volunteering; an interview with new trustee Ruthe Isden and more.

We hope you find the content interesting and that it keeps you up to date with NAC activities. We welcome any comments or ideas for articles – simply email [feedback@tnac.org](mailto:feedback@tnac.org)

Carolyn, Sue and Maggie, editorial team

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# Latest News From the NAC

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## Rowland Bareham, NAC Chair

### Update on Diageo Review Beneficiary Consultation

As explained in the last newsletter, the Diageo Review discussions are taking place this year. Before Christmas, I wrote to you all asking for your ideas about what to focus on in these discussions. I am pleased that we have had over 120 responses – many thanks to you all.

We are analysing the responses to summarise the ideas you have given us and will be discussing these with staff and trustees in the Diageo Chairs' Review Working Group. I will write to you in March to explain the shortlist that we will put to Diageo during the discussions.



### NAC Elections

You should have had a letter from Craig Millward, the Deputy Chair of the NAC, who is overseeing the elections process. This time, we have four vacancies on the NAC because Maggie Boyd, Nick Dobrik and I all reach the end of our current terms and are eligible to stand again. However, Maggie has decided not to do so, and Phil Williams has made the decision to stand down as an NAC member in March 2022.

This is a good opportunity for new candidates to come forward and I encourage you to think about standing for election. If you are interested in standing but still have questions, do come to a Zoom Q&A or talk to a current NAC member. Details from [feedback@ttnac.org](mailto:feedback@ttnac.org)

### Grünenthal Foundation

There is no further update at the moment on our ongoing dialogue with the Grünenthal Foundation about their grants programme.

Obviously, our historical connection with the German manufacturer of thalidomide is an emotional topic for us. That's why we want to understand your level of awareness of, and attitude towards, the Grünenthal Foundation and have included a question about this in the current Beneficiary Feedback Survey. Your answers will help to inform our next steps.

### Health Grant Renewal For Devolved Nations

Nearly a year ago, the Chancellor, in his budget, announced the lifetime renewal of the Health Grant for beneficiaries living in England. This announcement came very early – a whole two years before the start of the 2023/24 financial year, which is when the Health Grant renewal kicks in.

There have been no similar announcements yet for the devolved nations (Scotland, Northern Ireland and Wales) and we recognise the anxieties of beneficiaries in these nations given the lack of news. However, we are not unduly concerned at this time, given that the devolved nations have not yet developed their budgets for 2023/24 and are focusing on dealing with the Covid-19 pandemic. It's fair to say that the Chancellor's announcement for England came very early, rather than that the devolved nations are running late.

We continue to be in dialogue with officials in the devolved Health Departments and are maintaining the behind-the-scenes tactics that have proven to be effective in the past. Please be reassured that NAC, Trust staff and the trustees are keeping a close watch on this.

### **Comms/Admin Officer Leaving**

I'm sorry to have to tell you that Sarah is moving on. Sarah says:

“As well as working for the NAC, I write children's books. Before Christmas, I had a publishing contract for two new books, and I have decided I need to focus my time and energy on developing my career as an author, which means scaling back on other work. I have very much enjoyed getting to know the beneficiary community over the last year and have learnt lots from all of you. I will be doing a full handover with whoever takes over the NAC role.”

We have started a recruitment and selection process to find a replacement and I wish Sarah well with her writing endeavours.

### **Future Money Matters (FMM)**

The FMM events have been very successful in helping beneficiaries organise their finances, do some planning or simply offering reassurance by providing accurate information.

Our next FMM event will be online in June or July, with presentations recorded for beneficiaries to watch later – details to follow. Please contact Jeff Prevost at the Trust or Phil Williams at [phil@ttnac.org](mailto:phil@ttnac.org) if there are any issues you'd like to see included.

## **Committee Highlights: Health and Wellbeing**

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### **Carolyn Desforges, NAC Co-chair of the Health and Wellbeing Committee**

#### **Working Together to Live With Pain**

Report from The Pain Challenge Academy lecture by Paul Chazot, neuro-pharmacologist, and Dr Frances Cole, GP at the Wolfson Research Institute for Health and Wellbeing at Durham University.



Persistent or chronic pain is a huge health challenge, and the biggest reason why people in the UK see their GP. I had heard that the Trust's Holistic Needs Assessment (HNA) data shows that over 90% of the beneficiary community are living with some type of pain, so I felt it was important to listen to this lecture.

The Wolfson Institute has multidisciplinary teams working on understanding the symptoms of pain and how we perceive and experience it. They also research the application of medical or pharmacological interventions and social mediations in managing pain. It is now accepted that many current pain medications not only have limited use, but also have serious safety concerns.

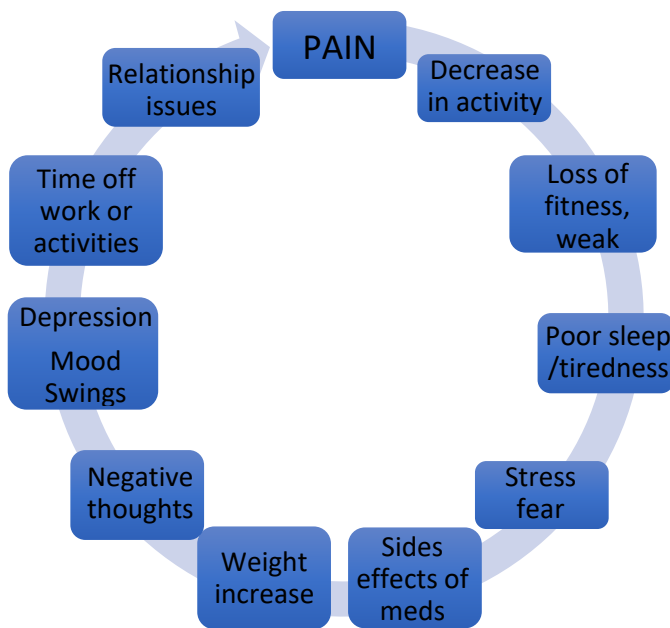
## Managing Our Own Pain

Persistent pain cannot be 'fixed' or 'cured'. To help manage it, there needs to be an understanding of an individual's experience and an individually tailored programme to help manage it. Healthcare professionals also realise they need to change how they engage with people with persistent pain.

However, whilst it is most helpful to have support in managing persistent pain, there are also ways in which we can start to understand our own pain and begin to think about our own ways of self-managing our pain.

First of all it is important to understand what is behind our pain, before beginning to manage it. The aim is to move from the pain cycle (see below) to a self-care cycle.

### The Pain Cycle – A Mix of Bio-Psycho-Social Issues



### Changing the Impact of Pain – the Self-Care Cycle



## Understanding Pain and the Brain

Our brain draws on our brain memories, but the system becomes over-sensitive and can give us an inaccurate interpretation. Persistent pain is very different from the kind of pain you experience when you injure yourself. It goes on long after the original damage has healed – it's as if the brain can no longer 'turn down the volume'. Reducing persistent pain involves retraining your brain. If we can figure out what is going on, we can then understand some changes that can help us manage the pain.

In Darlington, County Durham, a chronic pain management programme using a 'Skills not Pills' approach, has supported GPs, clinicians and pharmacists to implement a self-management programme to reduce pain, alongside implementing safe prescribing. The programme is called the 10 Footsteps Approach. Further information can be found at: <http://resources.livewellwithpain.co.uk/ten-footsteps/cover/>

It is important that we 'care' for ourselves, moving from **enduring** life to **enjoying** life.

### The 10 footsteps are:

1. Understanding how your brain is interpreting pain
2. Acceptance. This is not about giving in, but changing your focus towards what you want to do with your life – learning to manage the pain
3. Pacing. This is one of the key self-management skills for people living with persistent pain. Changing your pacing style could bring many benefits and lessen your pain
4. Setting goals. Having goals helps you to focus on the things that matter most to you – you must not forget to build in some rewards
5. Get more active. People with pain find it helps to be more active, even if it wasn't part of their life before pain. Getting support here to maintain motivation is key.
6. Managing moods. It is normal to struggle with moods when you have persistent pain. There are many ways to lessen the stress or pressure you're under. It is managing to discover which ones work best for you and then use them often.
7. Sleep. Lots of people with pain have difficulties sleeping, but making some changes to what you do during the day will help you sleep better – this includes what you eat and drink, your night-time routine, and having a 'fit for sleep' bedroom.
8. Food, relationships and work. Eating well, doing things with other people, and going back to work, or other retirement activities gives life routine, structure and purpose.
9. Relaxation and mindfulness. These can lessen pain levels, reduce stress and improve concentration.
10. Managing setbacks. People with pain experience setbacks for many reasons – and sometimes for no obvious reason at all. Having a setback plan ready can help you get back on track sooner – it is important to stay kind to oneself during these times.

There are some excellent resources to help support our self-management of pain to be found at <https://my.livewellwithpain.co.uk/resources/understand-pain/> Trust medical advisers and Health and Wellbeing staff can also offer support. Wishing you all the best for your self-care and a more enjoyable life less dominated by pain!

# Committee Highlights: Research

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## Positive News From the Exeter University Blood Pressure Study

### Phil Williams, NAC Member

Many people, who may feel well, are unaware of having high blood pressure (hypertension) until they have a cardiovascular event, such as a heart attack or a stroke.

Hypertension is one of the biggest risk factors for having a stroke or heart attack which is one of the largest causes of death in the UK. This risk increases with age and over 50% of people over the age of 65 have hypertension. Intervention to reduce hypertension has significant benefits.



So, it's invaluable to accurately measure blood pressure. But the traditional method of doing this is to take readings from the arm. For many thalidomide survivors and, of course, any other upper limb impaired or deficient people – whether from birth or as a result of accident or war – this can be challenging, potentially inaccurate or even impossible to do.

### Good News

The good news is that there is a solution on the horizon. Exeter University is working on a project to take readings from a leg and correlate this to an equivalent, regular, arm reading thereby creating a useful measurement for a clinician to advise patients on whether action is required to reduce their blood pressure.

The work receives substantial funding from The Stroke Association and a smaller contribution from The Thalidomide Trust. Two NAC members – Helen Shore and Phil Williams – are involved with this project, acting as PPI (Patient and Public Involvement in research).

There is real progress being made but, alas, these things do take time as there are so many regulatory and other hoops to jump through; not least the essential 'peer review' process.

The paper proposing the project was published in The British Medical Journal (BMJ) last year; Helen and Phil are co-authors to the amusement of several friends who are medical professionals yet to be published in the BMJ!

### Delivering the Changes in 2022

There have been presentations at various medical conferences – real and virtual – which have received very positive feedback and much interest. The second and final paper should be published before summer 2022 at the latest and then everything can go public.

Forget the academic side for a minute, what's happening in practical terms is something that upper limb impaired people need ASAP! A website has been created which contains the calculator which translates a blood pressure reading in the leg to a standard arm reading. Ultimately, it's planned to have an App.

There are plans in place to train nurses and a broad roll out plan as part of the dissemination strategy when everything goes 'live'.

Everyone is working very hard to deliver this life-changing and potentially life-saving tool to primary and secondary health professionals in 2022.

This is, of necessity, a simple overview and summary but if you are interested in more information, please do not hesitate to contact Helen Shore ([helen@ttnac.org](mailto:helen@ttnac.org)) or Phil Williams ([phil@ttnac.org](mailto:phil@ttnac.org)).

## In Focus: All About the NAC

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In time for the NAC elections, we've updated the info on the Trust website about what the NAC does, including a new video and downloadable factsheet.

The new NAC factsheet was either posted or emailed to all beneficiaries with the NAC election information earlier in January. It answers questions about how the NAC elections work, how long someone can serve on the NAC, how the NAC makes decisions, whether NAC members are paid and many more.

If you'd like to read the factsheet or watch the video, head over to this page: [www.thalidomidetrust.org/about-us/our-people/nac/all-about-the-nac](http://www.thalidomidetrust.org/about-us/our-people/nac/all-about-the-nac)

## Our Stories: Introducing Trustee Ruthe Isden

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### Maggie Boyd, NAC Member



Ruthe Isden joined the Thalidomide Trust Board of Trustees towards the end of 2021. As the newest trustee, we asked Ruthe to introduce herself to the beneficiary community.

#### **Can you tell us something about yourself?**

I've worked in public policy and influencing for nearly twenty years now, and I've spent the last ten with the charity Age UK working on health, social care, human rights and equalities issues in later life.

Apart from that, I live in London with my husband and five-year-old daughter. I'm a bit of a geek for social research into political trends in my spare time as well as outdoor bootcamp – the muddier the better!

#### **What attracted you to being a trustee of the Thalidomide Trust?**

After a decade in charity work I was really interested in using that experience to become a charity trustee. And when I saw this role advertised it seemed like a perfect fit. It's well understood we live in an ageing society with a growing older population. But what I think is less well understood is how diverse people's experiences of ageing really are.

I'm particularly passionate about making sure policy and services understand and respond to diversity so everyone can make the most of later life. Joining the Trust seemed like a brilliant opportunity to work alongside a group embarking on their ageing journey.

**What have you enjoyed so far about the role?**

Joining the Trust has been a great experience. I've had a wonderfully warm welcome from all the staff, fellow trustees and members of the NAC. Everyone has been very generous with their time and expertise, and I've learned so much already.

I've also really enjoyed getting involved in the conversations about the next five years and what the Trust needs and wants to achieve.

**Have there been any challenges so far in being a trustee?**

So far it's been pretty plain sailing, but I can see there will be challenges ahead. Over the next few years we need to prepare for the fact that the beneficiary community is getting older, and put in place the right plans to ensure everyone has the best possible practical and financial support heading into later life.

**Has anything been a surprise to you about the Trust and/or the beneficiary community?**

When I applied to join the Trust I was versed in the history of Thalidomide and the consequences for beneficiaries, but I knew nothing about the legal and financial settlements. Their size and scope did come as a surprise, and I think a real testament to the amazing work of all the beneficiaries, staff and trustees that have so consistently and successfully advocated on behalf of the community.

## Our Stories: Spotlight on Volunteering

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**Sue Gooding, NAC Member and Trust Volunteer**

We explore how volunteering within the Trust has changed and evolved over the years, and what volunteer opportunities are now available.

"There used to be a small group of 'Volunteer Visitors', but there are now an array of opportunities to volunteer to assist beneficiaries," explains Volunteer Coordinator Annabelle Blackham. "These draw on the wealth of different skills beneficiaries have to offer and enable individuals to learn new skills.

Annabelle continues, "Beneficiary volunteers come into volunteering for a variety of reasons. Some have retired and, with more time on their side, want to get more involved with the beneficiary community and others come to volunteering with a particular skill they wish to use to assist others. Stuart's experience, shared here, shows the difference that volunteering can make."

**Finding Out About Volunteering**

New volunteer, Stuart McLeod (pictured right), says that a conversation with Dr Susan Brennan sparked his interest in volunteering. Stuart has





always adapted items for himself to make his life easier and this skill combined with an interest in helping others inspired him to want to get involved. He also chatted with current volunteers about the satisfaction they get from being involved.

### **Applying to Become a Volunteer**

Stuart applied to be a Technical Volunteer for Aids and Adaptations. This involved completing an application form and attending an interview with a current volunteer and the Trust's Volunteer Coordinator, Annabelle.

Stuart found the prospect of an interview daunting initially having not been through the process for a while, but he soon relaxed and was able to discuss what skills he could share to assist beneficiaries. Stuart's listening and problem-solving skills are particular strengths he brings to his role.

### **Being a Volunteer**

Stuart's volunteering role takes up little time. It is not arduous, as it is doing something he enjoys. There is always support from Trust staff, but it is the support and encouragement from other volunteers that Stuart feels he has really benefited from. It has seen him re-connecting with people he hasn't seen since his teenage years. Life in general meant Stuart had lost contact with beneficiaries he had attended the same hospital as, and Society events many years ago.

### **The Benefits of Volunteering**

Stuart is finding the experience of volunteering rewarding and satisfying. He is enjoying feeling part of the community again, sharing knowledge and relating with others who deal with everyday challenges as he does. This, in turn, has reduced the feeling that he is the only person in the world dealing with a particular hurdle, which can be isolating. Stuart feels his confidence has improved since starting his volunteering role.

### **Find Out More About Volunteering**

If you want to find out more about volunteering at the Trust, get in touch with Annabelle by emailing her at [annabelle.blackham@thalidomidetrust.org](mailto:annabelle.blackham@thalidomidetrust.org) or by calling **01480 474074**. She can send you the Volunteer Pack, tell you more about the different volunteer roles that we now have and put you in touch with an existing volunteer, if that would be helpful.

## **About the NAC**

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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**

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We'd love to hear from you and include your stories and questions in the next newsletter in April. Email [feedback@ttnac.org](mailto: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](https://www.facebook.com/groups/ttnac)