

Inflammatory Neuropathies UK



IN brief

Latest from the Chief Exec

Spotlight on Fatigue

Christmas Card Competition

July 2026



IN brief

Chief Executive's Welcome

Rich Collins | Chief Executive

Summer has truly hit with some record breaking temperatures. I don't know about you, but I have been struggling in the heat, and the fans in my house and in the office have been working overtime. The heat can be a trigger for symptoms and residuals, so please try to stay safe, drink lots, and don't overdo it in the heat.

The temperature is not the only thing hotting up at the moment, with UK Politics being a bit of a hot topic. July will see us potentially having a new Prime Minister and a new cabinet, which will impact UK Policy. We are also expecting interim findings about benefits reform, so keep an eye on socials and the website for updates on how all this will impact people with Inflammatory Neuropathies.

Talking of benefits, we have had some really excellent early results for people who have accessed our new Benefits and Welfare Service. Tansy has worked with a number of people so far, and has secured some big financial wins for them. If you think she could help you, then please get in touch via **hello@inflammatoryneuropathies.uk**.

The team have been out and about in June, representing the community both in the UK and abroad. You can check out what we have been up to on our social media (@inflamneurouk), but we will be writing it up and sharing in the next In depth newsletter in September, when we have a bit more space.

In the meantime, stay well, and take care.

Rich

SAVE ^{THE} DATE

Don't forget that this year our AGM and Big Get Together will be in Bristol on Saturday 3rd October.

Don't forget to pop the date in your diary, and we will give you more details soon.



IN the spotlight

Focus on: Fatigue – your needs and recommendations

We've been chatting to lots of you recently about one of the most common and frustrating symptoms of an inflammatory neuropathy: fatigue. It's been so helpful hearing your views and queries, so we've pulled it all together and wanted to let you know our plans to better support our community on this.

In our conversations you told us that:

- **Fatigue is as debilitating when its mental /cognitive as well as physical.**
- **It also causes real difficulties with your employment, with housework and childcare – any over exertion or activity is followed by needing days in bed to recover.**
- **We had lots of questions about research into what works for fatigue as there's currently no treatment for it (unlike pain).**
- **You also asked us for more resources to support you with employers and needing time off.**
- **Many of you wanted recommendations for effective supplements and any alternative remedies that might work. We also had questions on how your family or carers can best help and support you.**

So we're delighted to share that we're following this up and are currently developing some new resources on fatigue management! We're speaking to specialist employment advisers about your rights at work, and we're exploring working with nutritionists and physiotherapists to create some bespoke resources on diet and lifestyle changes to help. We're also going to be commissioning our own research into the best methods for preventing, managing and reducing fatigue.



For now, here are a few suggestions based on NHS and NICE guidelines on how best to manage symptoms:

1. Pace yourself- build in regular breaks and rest days.
2. Adopt good posture. Physiotherapists can advise on efficient movement and positioning strategies.
3. Avoid relying on caffeine if you can and make sure you stay hydrated.
4. If you can, do a little gentle, regular exercise (guided by a specialist neuro physiotherapist) – this can actually help manage fatigue over time.
5. Good sleep hygiene, balanced nutrition and stress reduction all play a role in managing fatigue effectively.
6. Keep cool- this is obviously very topical right now but did you know it takes energy to cool your body temperature?

So watch this space for more resources and information on this subject soon!

IN the festive spirit

Christmas Card Competition

Hang on, I hear you cry, it's July, it's summer time, it's hardly Christmas!!

Well, over here in Inflammatory Neuropathies UK HQ, we have to start thinking about Christmas early. We are already getting emails from card manufacturers and distributors trying to sell us their latest designs.

However, following on from the success of last year's Christmas Card Competition, we want to carry on the theme of creating bespoke cards for our amazing Inflammatory Neuropathies Community.

So, what is the ask? It's fairly simple, get out your paints, pencils, pastels, or crayons, or fire up your digital device if you are that way inclined. Engage your inner Hockney, Picasso, or Michaelangelo, and create us a masterpiece.

We don't care if you are young or old, a regular artist or a newbie, everyone's efforts are worthy of a place on our Christmas Card. All we ask is that your design is as Christmassy or Wintery as possible, and that there is nothing rude on it. Make them cute, make them funny, make them beautiful (word of advice – everyone likes a Robin), and send them in. You could see your design on our actual Christmas Card.

Last years winners!



Send in your design via email (high quality scans are best for this)

to hello@inflammatoryneuropathies.uk or preferably in the post to:

Inflammatory Neuropathies UK, 3 Mill House, Carre Street, Sleaford, NG34 7TW

Entries must be in by Monday 31st August, when our judges will choose their favourite.

Best of luck!

3 Mill House, Carre Street, Sleaford, NG34 7TW

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**IN this
together**

Inflammatory Neuropathies UK

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