

gain4all

Issue 7

Quarterly magazine of Guillain-Barré & Associated Inflammatory Neuropathies

AUTUMN 2015



www.gaincharity.org.uk

gain4all

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Thank you



about Guillain-Barré syndrome

Guillain-Barré syndrome (GBS) is an inflammatory disorder in which the body's immune system attacks the peripheral nerves.

Severe weakness and numbness in the legs and arms characterise GBS. Loss of feeling and movement (paralysis) may occur in the legs, arms, upper body and face. Severe cases may result in total paralysis and breathing difficulties, requiring long-term rehabilitation to regain normal independence, with as many as 15% experiencing lasting physical impairment.

In some cases, GBS can be fatal. Because the cause of GBS is unknown, there is no way to prevent the disease from occurring.

CIDP

Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) is a disorder related to GBS that follows a much longer course. Though rarely fatal, many patients seek an effective treatment that often proves elusive.

about gain

GAIN is a registered charity that supports those affected by GBS, CIDP and other related conditions in the UK and Ireland. Please contact us for further information or support.

The charity has three main aims:

The provision of information, non-medical advice and other assistance;

The promotion of research into the causes, prevention and treatment of Guillain-Barré syndrome and associated inflammatory neuropathies; and

Advancing the awareness of the public and of the medical professions concerning Guillain-Barré syndrome and associated inflammatory neuropathies, their causes, prevention and treatment.

How you can help

As long as people continue to be taken ill by GBS and CIDP, the Charity's work will never be complete. We can only continue to provide our service with the continuing help of our generous supporters. There are several ways in which you can help us and make that extra difference.

- Fundraising
- Make a financial donation
- Become a member
- Volunteer

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0800 374 803 (UK)
1800 806 152 (ROI)
Registered Charity 1154843 & SCO39900

Report from our Regional Event (York)

Saturday 10th October

GAIN held its third regional event at Woodlands Neurological Rehabilitation Centre, York (part of the Christchurch group) and attracted around 25 members and their families to come along. Members had an opportunity to chat over a coffee on arrival and then Caroline led a lively discussion on what was new with the office and neurology in general. Following a buffet lunch we were joined by our guest speaker Rob Poppleton, a Consultant Clinical Neuropsychologist from Christchurch Group, based at Hunters Moor in Birmingham. He is a respected neuropsychologist with a particular interest in outcomes measurement and the management and assessment of those with complex brain injury.

Rob started by talking about the different levels of rehabilitation that are available here in the UK.

- Level 1: Regional specialised centre for rehabilitation services for patients with highly complex needs
- Level 2: Local specialist rehabilitation services (general hospital) with a lower proportion of complex cases
- Level 3: Non-specialist rehabilitation services (community care / nursing homes, etc)

Patients suffering a sudden onset condition such as Guillain-Barré syndrome, or a related inflammatory neuropathy, would commonly give rise to complex disability during the recovery period. However, diagnosis alone is not the best determinant for rehabilitation as much depends on levels of impairment and complexity of needs for rehabilitation. For patients with highly complex needs, a level 1 unit would offer the most appropriate rehabilitation opportunities. There are currently 14 level 1 units in England with 8 of these being in and around London.

Although considered a vital part of recovery, very few Acute hospitals employ clinical psychologists, and they are mainly at the rehabilitation stage particularly if referred to Level 1. Two people spoke very highly of the service they had received in terms of physiotherapy and neuro-psychology and 2 different hospitals. Rob said that the outcome often depended on a number of factors, including the personality of the patient, as well as the amount of support from their family. Not everyone is able to benefit from family support of course, and Rob acknowledged that this can have an effect on a person's recovery.

There was a great deal of discussion amongst the audience as to how much physiotherapy a patient



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The next issue of the magazine will be published in January 2016 and the deadline for submissions is 16 November 2015. Please forward all articles to Lesley Dimmick fundraising@gaincharity.org.uk

from the office

should receive. It would seem that expectations of rehab are often unrealistic and could perhaps be communicated better by medical staff. In a Level 1 unit, there would be a maximum of 30 hours accompanied physiotherapy per week, but it is far more likely that a patient will receive 20 minutes each day, or maybe 1 hour, 3 times per week, to be supplemented by ongoing exercises for which the patient is responsible, perhaps with the support of family or a member of the nursing team. Little and often is likely to be more beneficial, so patients need to try to build up their strength with daily exercises, and not only when they see their physiotherapist.

Ideally, following discharge, a patient should expect ongoing physio at their local hospital or at community level. It may be possible to access NHS-funded exercise programmes at the local gym or swimming pool, so it is worth asking your GP if this is available. Rob stressed that rehabilitation is not a spectator sport, and you must put the effort in order to gain the most benefit. However, it is also important to rest, as overdoing it and pushing yourself too far may prevent you from being able to exercise for the next couple of days. Physiotherapy should be 7 days a week, so even if you only have access to a physiotherapist

once a week or once a month, make sure you have exercises you can do yourself between visits. If your entitlement to guided physiotherapy has come to an end, it is important to keep motivated and keep doing the exercises. You don't need special equipment, improvise with tins of beans or bags of sugar!

In order to combat fatigue (physical) and build stamina (mental), structure and planning is key. Little and often is best, and if you learn to pace yourself and structure your day, you will find that stamina and fatigue levels will gradually improve. Remember the 5 'Ps' (more often extended to 6 'Ps', but shortened here to 5, so as not to cause offence!); **Prior Planning Prevents Poor Performance**

We all have limits. You had limits before your condition, and now you have different limits. If you live with the condition, not through the condition, you can put yourself in control and not be ruled by it. Ignore what you can't change. Do what you can, instead of dwelling on what you can't, but at the same time know your limits.

Recovery from serious illness or living with a long term, life-changing condition can produce the same emotions as grief. The 5 stages of grief are

cont over...

gain²gether Glasgow 2016

Join us for this special event to celebrate the centenary of Drs Guillain and Barré's research to be held in the historic Glasgow University on 25 June 2016. Following a major international neurological conference hear world renowned speakers and meet people from international support groups. This is an opportunity not to be missed. You are welcome to join us on the Saturday evening in one of Glasgow's famous eating houses.

Sunday is a day for the Golfers with a competition which will raise much needed funds for the Charity.

We are expecting a good turnout and

would advise our members to book their accommodation early. There are a number of hotels and guesthouses in the West End of Glasgow within easy reach of the University and details can be found via Visit Scotland either by phoning 0845 8591006 or looking at the website <http://www.visitscotland.com/info/services/glasgow-information-centre-p332751>

More information will be printed in the magazine and on the website as we confirm the details



DENIAL (can't be true, this isn't happening), ANGER (why me?), BARGAINING (if you can manipulate the situation it will go away), DEPRESSION (it's all hopeless; my life is over) and ACCEPTANCE (re-structuring and living life within new limitations).

There is more than one type of depression and not all types of depression can be successfully treated with medication. Severe illness or disability, along with many other factors, can cause reactive depression, which is a response to something bad happening. Unlike endogenous depression, which is caused by a chemical imbalance that can be corrected, reactive depression often won't respond successfully to medication, which is why neuropsychology plays such a vital role in recovery.

Behaviour might change and a patient may feel worthless and want to avoid people altogether, which isn't good for recovery. Socialising should be encouraged. Regular exercise can improve mood as well as fitness levels, but look out for the early warning signs of 'overdoing' it, such as aching muscles, etc. Eating a healthy diet can also help.

Maintaining a positive mental attitude helps a lot, especially in conjunction with the support of family, and having a good laugh really does take some of the pressure off. *[At this point, Rob told some truly awful jokes, to be matched by several more from the floor, and accompanied both by moans and much chuckling]*

A question was asked about what happens to a relationship when a partner becomes the carer. There seem to be positives and negatives, with some couples becoming closer and stronger, and others breaking down. Statistics show older, more established couples fare better whereas younger couples don't do so well. Although the theory would suggest it is better that the partner doesn't become the carer, in reality, it often works out that way, either by choice or necessity.

Rob finished by saying patients should think of coming through rehab as The New You.

You are living through and surviving a tough situation. Take credit and be proud of yourself.

For further information on discharge from hospital, rehabilitation and NHS continuing healthcare, visit the NHS Choices website www.nhs.uk

Dates for the diary 2016

March	Regional Meeting
25 June	Centenary <i>gain2gether</i> to coincide with the Inflammatory Neuropathy Consortium meeting and symposium
26 June	100 Golf Day
September	AGM and Regional Meeting

Full details for all of the above will be issued in the next issue of *gain4all*, on our website and through the usual social media channels.

IN MEMORY

Christos Lazari

Christos Lazari was an inspirational person. He was always hopeful about the human potential and had the courage and conviction to fulfil his. He was father to a daughter long challenged with CIDP. As a parent, he warmly supported and encouraged his daughter and his heart went out to people challenged by similar neuropathies and their families. He always prayed for a cure and a better understanding of the disease. Donations in his memory will hopefully help answer his prayers one day. Though he is silent now, the sound of his being; his strength; his ethos and teachings resonate with all the lives he touched.



Meet the Medical Advisory Board (MAB)



1. Who are you?

Dr Claire White, a physiotherapist with a longstanding interest in rehabilitation for people with long term neurological conditions.

2. Where do you work?

I am Senior Lecturer at King's College London in the Division of Health and Social Care Research and the Academic Department of Physiotherapy. Within my teaching role I help students to become evidence based practitioners by ensuring that research evidence forms part of my teaching. This means that students at King's learn about GBS and CIDP management including current research developments. Resources available via the GAIN website are also very helpful in helping students become more aware of the experience of illness and recovery from acute GBS and of living longer term with the consequences of GBS and CIDP.

3. What is your role on the MAB?

My role on the MAB is to contribute and advise on physiotherapy and rehabilitation for people with GBS, CIDP and other forms of IN. This can be in response to specific questions from members or as part of the information available on the website and other publications.

4. Do you have a special interest in GBS/CIDP or one of the variants?

I am interested in Physiotherapy and rehabilitation for people with GBS/CIDP and in particular in trying to improve the long term consequences for

people living with these conditions. I am leading the ongoing HINT trial (Home exercise for Inflammatory Neuropathy Trial) with a MAB colleague Dr Rob Hadden as well as Dr Jane Petty the trial co-ordinator. We hope to report on the findings to GAIN in 2016.

5. What inspired you to join the MAB?

I was invited to apply to join the MAB by Professor Richard Hughes (current patron) when I was lucky enough to have been working with him whilst he was Professor of Neurology at King's. I was pleased to be able to contribute to the charity in this way and it gives me an opportunity to raise the profile of physiotherapy and rehabilitation including any developments in research or practice.

6. What current global research excites you?

There is not enough research into physical rehabilitation in GBS and CIDP but earlier research in Australia by Prof F Khan was the first to show that multidisciplinary rehabilitation treatment programmes that include exercise and walking as well as occupational therapy and psychological support can reduce disability after GBS. In addition, there is a wealth of research into the health benefits of physical activity in general as well as studies examining how cognitive behavioural approaches can help people manage their symptoms or adopt healthier behaviours. This evidence shows that increasing physical activity can significantly reduce the likelihood of many health conditions associated with ageing including heart disease, obesity and diabetes. Interestingly, other research shows that reducing the time spent being sedentary ie in sitting is also essential to get the most benefit. What is exciting about these findings is that they may be important for people with GBS or CIDP where mobility is affected but where even small but consistent efforts to increase physical activity may be beneficial.

7. Finally do you see a time when GBS and CIDP are preventable?

I suspect that other MAB members will have a more accurate prediction for this but until prevention or cure is a possibility there remains an important role for effective support and management of symptoms for people with inflammatory neuropathy.



Seasons Greetings

As the next issue of *gain4all* will not reach you until the New Year, the trustees and staff of GAIN would like to thank everyone for all their help and support throughout 2015.

The office will be closed from 12.00pm Thursday 24 December until 9.00am Monday 4 January 2016. The 24 hour helpline will operate throughout the Christmas and New Year period and urgent emails will be monitored and dealt with throughout.

COUGHS & SNEEZES

spread diseases



Flu is not a 'bad cold'. Each year, thousands of people die of complications after catching the flu.

Flu is a common infectious viral illness spread by coughs and sneezes. It can be very unpleasant, but most people will usually begin to feel better within about a week. However, for those considered to be in a 'high risk' group, flu can be fatal, and so their GP will recommend they are vaccinated against the most prevalent strains of flu predicted each year.

People have varying opinions on the subject of vaccinations, and unfortunately, there is a huge amount of scaremongering around which is both damaging and misleading. Studies in the UK have shown no causal link between the seasonal flu vaccine and GBS, although there is a strong association between GBS and influenza-like illness. This year more so

than in previous years, organisations such as Public Health England and the World Health Organisation are advising people that the risk of getting GBS as a result of having flu far outweighs the risk of getting GBS from the seasonal flu vaccination.

Because a very slight chance cannot be totally ruled out, you may still see GBS listed as a possible adverse reaction on the patient information leaflet that accompanies the vaccine. However, this risk equates to an estimated one possible extra case of GBS per million flu vaccinations as opposed to the one in sixty thousand cases of flu that results in GBS. It is believed that one of the best ways to protect yourself against GBS is to take steps to protect yourself against flu.

The decision to have a vaccine depends on your individual circumstances and you should always discuss this with your own doctor.

COLD OR FLU?

Symptoms of a cold include:

- runny nose
- blocked nose
- sore throat
- sneezing
- cough

People with a cold may also suffer with a mild fever, earache, tiredness and headache.

Symptoms develop over one or two days and gradually get better after a few days. Some colds can last for up to two weeks.

According to the Common Cold Centre in Cardiff, a cold is most contagious during the early stages, when the person has a runny nose and sore throat.

Whether it's a cold or flu, get medical help if you either have a chronic condition (such as asthma, diabetes or heart disease) or have a very high fever as well as an unusually severe headache or abdominal or chest pain

Flu usually comes on much more quickly than a cold, and symptoms include:

- sudden fever of 38-40C (100-104F)
- muscle aches and pains
- sweating
- feeling exhausted and needing to lie down
- a dry, chesty cough

A person with flu may also have a runny nose and be prone to sneezing, but these are not usually the defining symptoms of flu.

Flu symptoms appear one to three days after infection and most people recover within a week, although you may feel tired for longer. A severe cold can also cause muscle aches and fever, so it can be hard to tell the difference.



THE FLU VACCINE

A flu vaccine is available for free on the NHS for:

- anyone over the age of 65
- pregnant women
- anyone who is very overweight (with a body mass index over 40)
- children and adults with an underlying health condition (particularly long-term heart or lung disease)
- children and adults with weakened immune systems

An annual flu vaccine nasal spray is also now offered to healthy children aged two, three and four years old, and to children in school years one and two.

The best time to have the vaccine is in the autumn, between September and early November. If you think you might need it, contact your local GP surgery.

You should have the flu vaccination every year so you stay protected, as the viruses that cause flu change every year.

Further information

There is lots of information about flu and the seasonal flu jab on the NHS Choices website and in the Green Book published each year by Public Health England (website links below). If you are in doubt, read up on it and talk to your doctor so you can make an informed decision that is right for you and your circumstances.

NHS Choices

www.nhs.uk/conditions/vaccinations/pages/who-should-have-flu-vaccine.aspx

Green Book Chapter 19 (see page 23-24 for info about adverse reactions)

www.gov.uk/government/uploads/system/uploads/attachment_data/file/456568/2904394_Green_Book_Chapter_19_v10_0.pdf

REPORTING OF SIDE EFFECTS

If a vaccine is suspected of acting as a trigger, then this is determined via a serology test and the vaccine reported under the Yellow Card Scheme (UK) or HPRA Pharmacovigilance (Ireland).

United Kingdom

Yellow Card Scheme
Vigilance and Intelligence Research Group
Vigilance and Risk Management of Medicines
MHRA, 4.M, 151 Buckingham Palace Road,
London SW1W 9SZ

Tel: Freephone 0808 100 3352
Email: yellowcard@mhra.gsi.gov.uk
Website www.mhra.gov.uk/yellowcard

Ireland

FREEPOST
HPRA Pharmacovigilance
Earlsfort Terrace
IRL – Dublin 2

Tel +353 1 676 4971
Email: medsafety@hpra.ie
Website www.hpra.ie

London to Paris Bike Ride

4-7 September, 2015



fund

After my daughter Amy was born with CIDP, four years ago, I always knew I wanted to do something for GAIN to give something back for all the help they gave us through the hard times.

Having not ridden a bike for years I thought the perfect challenge would be a 234 mile bike ride from London to Paris!

Day 1

85 miles: London-Portsmouth.

After nervously setting off from York house at 8.00am it all started out as a nice flat ride but everything changed after lunch, we were then riding hill after hill with the steepest gradient being 21%. Thereafter, the ride into Portsmouth was generally flat and we were able to shower before rolling down to the docks to take an overnight ferry across to Caen.

Day 2

87.5 miles: Caen-Evieux.

We only had four and a half hours sleep on the ferry; it was safe to say it was going to be a very long day ahead. Starting at 6:45am as the sun rose, there was a very cold chill in the air and wearing short sleeves was not a good choice. However, Day 2 was a little easier than the first apart from two very long climbs at around the 20 mile mark, and very long they were too! After this it was a very pleasant ride through the French countryside and little villages until we reached our hotel for the night.

raising reports

Day 3

68.8 miles: Evreux-Paris.

WOW what a day!

The whole route was generally flat again on cycle paths through the countryside with the odd historic village; we stopped for lunch approximately 20 miles from Paris then carried on riding until near the Champs-Élysées where we regrouped for our final stretch to the finish line at the Eiffel Tower.

This final stretch was one of the most amazing experiences I have ever had to date, there are honestly no words that could ever explain how it felt, adrenalin had taken over; there could have been the biggest hill to climb and it would have felt like a lump in the road.

I was riding with people I had never met in my life, from all over the world, but after being with them for 72 hours it felt like I had known them a lifetime, all of them had heard our story and couldn't wait to meet Amy. Emotions got the better of me when it came to



the finish where my wife Sam, Amy and my parents were there waiting for me. Having a picture with Amy under the Eiffel Tower ripped me to pieces – after all, if it wasn't for her I would never have been doing this challenge and if it wasn't for team Phenomenex and the other guys on the ride, it wouldn't have been the enjoyable ride it turned out to be!

So this was a little thank you from our whole family to you at GAIN for all of the support you gave us during our tough time and now the question is what to do next...

Darren Parr



Darren with Sam and Amy





Jessica

Prudential RideLondon – Surrey 100

The 2015 Prudential RideLondon-Surrey 100 took place on 2 August and thanks to our four riders Jessica, and Robert, Ross and Ben (members of the Ecoshred 5 Peak Charity Challenge team) over £5000 has been raised for GAIN and the total is still rising. This is a fantastic amount of money and a big thank you to our riders and everyone who supported them.



Robert, Ross and Ben

The 2016 Prudential RideLondon-Surrey 100 will be on Sunday 31 July and we have six Charity places. There is a registration fee of £45.00 and minimum sponsorship is £750.00 and again, all money raised at this event will go to much needed medical research.

If you would like to take part in the best celebration of cycling in the UK and would like to support GAIN, please get in contact with us.

For an application form contact Lesley Dimmick,
T: 01529 469912 or email: fundraising@gaincharity.org.uk



Dragon Ride in the Brecon Beacons

I was really pleased to have recently raised over £500 for GAIN by completing the The Dragon Ride in the Brecon Beacons, South Wales. My Dad was diagnosed with CIDP a few years ago and since then I have realised how much people rely on GAIN for information and support to help them cope with these little known diseases. The ride was great fun and tough in equal measure, with fantastic views and steep mountain roads. My Mum and Dad popped up along the route with extra bananas and were there to see me over the finish line after 140 miles of riding. Overall, it was a great day and the fact people were so generous with their sponsorship was a real bonus.

Anthony Price

Coast 2 Coast in a day

I really enjoyed the ride however it was an extremely hot day which drained most of my energy and no ice cream van in site.

I finished in just over 12 hours and was pleased to be raising some funds for a worthwhile charity such as GAIN. I thank Kelly Hindson for her encouragement and her inspiring fight to live a normal life while dealing with her affliction.

Craig Howells





Left to right: The Sloemotion Walking Team – Will Illingworth, Pippa Moore, Julian Curtoys, Adam Szczecina, Adam Cook, Jordan Cook & Ian Mansell (and Jonathan Curtoys – the photographer!)

Yorkshire 3 Peaks Challenge

On 13th August at 7.45am we set off on the 39km walk from Horton-in-Ribblesdale in North Yorkshire, climbing the first peak, Pent-y-Gent (691m), reaching the summit at 10ish. It was then a long, but glorious, walk over to Whernside, passing the amazing Ribbleshead Viaduct on the famous Settle-Carlisle railway line (seeing a wonderful steam train pile over and on into the 2.5km Blea Moor Tunnel). Fortunately for us it was a glorious day for walking, bright and sunny, but not too hot. We reached the summit of Whernside (728m) at about 2pm. It was then on to Ingleborough (723m) for the last summit, including a very steep, arduous, muscle burning straight up scramble, reaching the top at 5.30pm. Thankfully the last 6km back to Horton was all downhill, through wonderful limestone pavements. We were back in time and with enough energy to have a celebratory

pint or two. Four of us managed finish in under 12 hours which means we qualify to join the Yorkshire Three Peaks Club.

The walk was all done in the memory of Julian and Jonathan's Mum, Barbara Curtoys. In January 2015 Barbara began to suffer the first symptoms of Guillain-Barré syndrome and sadly died from related complications on 5 June, her 84th birthday. Barbara was an unusually active octogenarian – still working a few days a week for the Curtoys' business, Sloemotion Ltd, doing tastings of Sloe Gin and their other liqueurs in farm shops and delis from Cumbria down to Gloucestershire! You might notice a bottle in the image from the summit of Whernside – we all drank to Barbara with our favourite liqueur at the top of each hill! In the last 10 years Barbara had also completed a number of degrees at the Open University whilst also regularly looking after her grand-children and a lot of "old ladies" in the family – most of them younger than her! To see such a rapid decline in Barbara's health was a tragedy. In the end her death, from a small heart-attack, was a mercy to stop her suffering – she didn't like being a patient and couldn't bear the inactivity, but we all miss her terribly.

We hope to be doing more events over the coming years to raise money for GAIN, helping much needed research into this dreadful illness.

Jonathan Curtoys

Well, what a night!



Lead singer Bob Arnold

Yes, once again we held another charity fundraiser on 12 September at Amasal Social Club in Stafford for GAIN. We had live music, fantastic raffle prizes and spot prizes for those who looked like they were having the most fun! It was an amazing evening. We raised a whopping £1,412.50 which is an incredible amount. Thank you to all my GAIN friends who came and supported us and to all my friends and family – I couldn't have done this without you.



Dad (left) with my fiancé John



Mum (left) and my sister

“ Without these four, I wouldn't be where I am today. ”

On Sunday 4 October, I completed the Chester Marathon in 4 hours, 59 minutes and 17 seconds and I, Sally Haycock am a Guillain-Barré syndrome survivor!

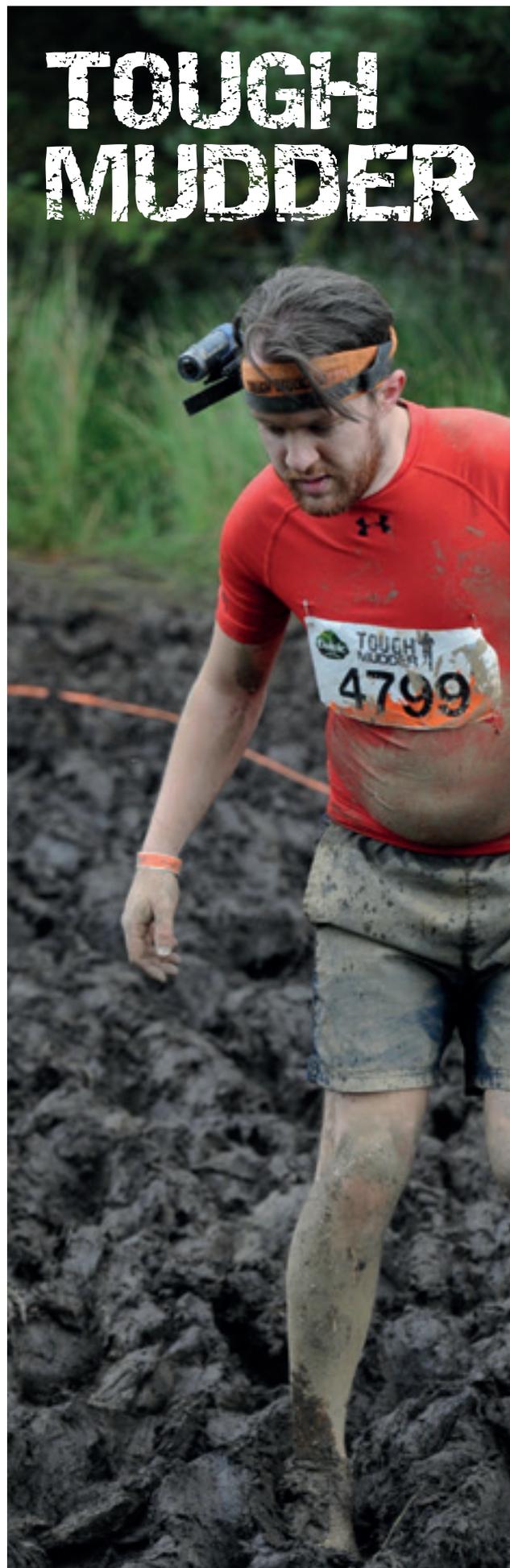
Diagnosed in January 2013, I spent three long months in hospital and had a whole year off work, but I had always enjoyed running and indeed was training for my second half marathon when I came down with this illness. I had never considered

running a full marathon before being ill, but there are several things this illness has taught me and that is to be brave, fear nothing, challenge yourself and enjoy life every step of the way.

Completing the Chester Marathon was a phenomenal experience and something I will never forget. Whilst running the marathon I spoke to several people about my illness thus raising awareness with every step! I was also overwhelmed by the stories people told me about why they were running, the whole experience was extremely emotional. I feel immense pride in what myself and every runner achieved that day and I hope anyone reading this is inspired! So far fundraising for this has reached £900 with donations still coming in.



Sally Haycock





My Nan (Sheila Spittle) was an amazing woman. Her strength, determination and outlook on life were inspirational. She was an active lady who enjoyed arts and crafts (made all of her own lovely cards), going to the theatre and spending time with family and friends.

One day her legs gave way and she was taken to hospital. The hospital said she had gall stones but there was something else that they needed to look into before they could treat them. Her condition deteriorated and she was taken into intensive care where she was diagnosed with GBS. None of us had ever heard of it before and we were left confused and in shock. Although her condition didn't seem to be improving, the doctor told us not to expect that she would die from this and that everything was treatable. However, later that day, 12 August 2014 Nan's condition rapidly deteriorated and she had a cardiac arrest. There was nothing more they could do for her so it was decided that the machines be turned off and she passed peacefully with her family around her.

I'm not a huge fan of running but when I saw Tough Mudder, I immediately wanted to take part and completed my first one in 2014 which was whilst Nan was in ICU. When I was there, covered in mud and aching, I was amazed by it all and pledged to do at least one more. My Nan was so proud of me for completing it (but also thought I was crazy for doing it) which spurred me on to take part in the 2015 event (I said she'd have to come and do the next event with me and she laughed. She said "don't worry, I'll be there").

I did volunteer this year and will be taking part again in 2016. The determination and strength required to complete Tough Mudder, reflects that of my Nan. Tough Mudder is linked with Help for Heroes, well Nan will always be my hero. So running in memory of her, I take part in Tough Mudder to raise funds and awareness for GAIN. I hope that, by doing this, more awareness will be out there so that nobody has to have the confusion that we had when Nan was diagnosed.

Tough Mudder is a team-oriented 10-12 mile (18-20 km) obstacle course designed to test physical strength and mental grit. The obstacles are designed by British Special Forces. Tough Mudder puts camaraderie over finisher rankings and is not a timed race but a team challenge that allows participants to experience exhilarating, yet safe, world-class obstacles they won't find anywhere else.

Dan Sutton

Fundraising performance

Professional harpist, Victoria Longhurst performed at Baldwin's Travel Agency on the 23 July and very kindly donated her fee to GAIN.



Hull 10k

Arran Hayes ran the Hull 10k for his father who earlier this year was diagnosed with GBS.

'He is now eight months into recovery and has started back at work on half days teaching new army recruits how to drive! We are all very proud of him and how he has dealt with this horrific disease and the issues it has caused him.' said Arran.



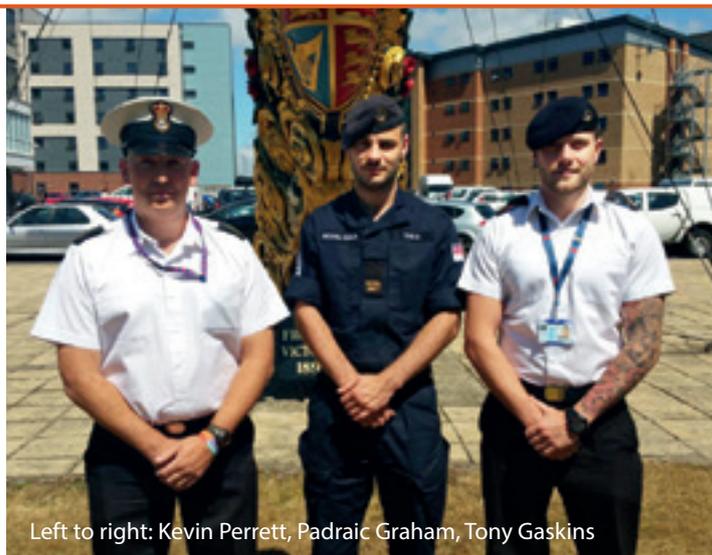
Sailors Three in Fundraising Marathon

When Royal Navy Petty Officer Kevin Perrett casually announced his intention to run the South Downs Half Marathon he wasn't expecting to generate much interest from his two colleagues, AB Tony Gaskins and AB Padraic Graham. Kevin, an experienced runner, is in charge of the gunnery office at HMS Nelson in Portsmouth and was intrigued when Padraic announced that he was interested in taking part and they should enter as a team to raise funds for the GAIN charity.

As with the majority of people until they personally encounter GBS, Kevin and Tony had not heard of the illness but once Padraic explained what it was and how it had affected his father, they immediately agreed to run for the charity. Kevin set up a JustGiving page on the internet and sent off for application forms while Padraic engaged with GAIN HQ in Lincoln to formalise their entry, obtain charity emblazoned running vests, wrist bands and a supply of raffle tickets.

The event took place on Saturday 20 June starting and finishing in Queen Elizabeth Country Park near Petersfield in Hampshire. Padraic's parents, Phil and Janet, drove from their home in County Durham to witness the start and finish. Kevin and Tony's families were there too and were most interested in hearing first hand from Phil about GBS and its impact, not just on him, but on family members as well.

The three runners had noted in advance that the South Downs Half Marathon was to be run over steeply undulating chalk countryside, with deeply rutted uneven paths underfoot, whereas the majority of other similar events usually take place over fairly even and flat ground in and around towns and cities. Knowing this they had trained specifically for what lay ahead.



Left to right: Kevin Perrett, Padraic Graham, Tony Gaskins

With a sizeable crowd looking on the race got underway at 10.30am following a start for juniors and families a few minutes earlier. The weather was overcast, breezy but warm as the first of the runners crossed the line just over an hour after the start. Padraic was the first of the three Royal Navy runners to finish followed by Kevin and then Tony.

Exhausted but delighted with their efforts, the three proudly displayed their entrants' medals for family photographs. Phil, who had spent ten months in hospital with GBS and who is slowly recovering at home, said he was delighted with the three runners.

"My son has seen how GBS has affected me and how it has impacted on Janet, too. I am so proud that he chose GAIN as the charity for this run." Janet, too, was full of praise, adding, "I can't thank Kevin, Tony and Padraic enough. They have been marvellous in their support for GAIN."

All in all some six hundred pounds was raised through Just Giving with an as yet unknown additional amount received through personal donations from elsewhere.

Kevin Perrett summed up the mood of the day announcing, "That was the hardest run I have ever done but knowing that we are helping such a relatively unknown, but highly worthy cause, made it all worthwhile."

Phil Graham



Team Tony

In April 2014, Tony Curry was struck down by a very severe form of the condition, Miller Fisher. Whilst on holiday in Wales he became ill, was rushed to hospital and within 24 hours, was in Intensive Care. Tony was totally paralysed, he remained in a coma for a month and was ventilated for nine months. He has since moved to a rehabilitation centre and is having continuous physiotherapy to regain strength and movement, and with the help and support of his family and friends, is working towards being able to get back on his feet and walk again!

Team Tony is raising money for Tony to support Forest Hall Football Club and GAIN (to be divided equally). For the past sixteen years, he has been and still is involved in Forest Hall FC

and is currently Chairman. Money raised will be used to support and run the club and to help keep all children, teenagers and adults involved in the community and by creating a better place, the football club can help them to develop and grow. Tony and his family also wish to raise funds for GAIN to help support other people and their families who are affected by this devastating illness, to raise awareness of the condition and to help fund research.

Following a charity match in March held by Terry Denwood, a fundraiser at their local social club with the Gatecrashers band in September and various other fundraising activities and events, including the Great North Run, over £4000 has already been raised and the figure is still rising.



Tony with family and friends

JUMPING from 15000 feet

19 September was a beautiful sunny day! Unfortunately I was facing my fears! I did a skydive at 15000 feet at my local skydive centre in Durham. It was very surreal doing something which was utterly terrifying but amazing at the same time!

I wanted to do something to challenge myself (I turned 40 on the 24 September) and this crazy idea seemed just the job. My mum had suffered from GBS in 2012 and we will remember the terror we felt at this unknown debilitating syndrome. We are incredibly lucky that my mum made a full recovery and she can enjoy her grandchildren. I wanted to do this to raise money for GAIN to raise awareness of something of this cruel and frightening syndrome.

Irene Hall





Climbing

after eight of a total ten plasmapheresis treatments I turned a corner and started to get stronger, after fifteen days I was able to walk with the support of a nurse and a zimmer frame.

I was then flown on an air ambulance back to Wales where I spent a further four months in a neuro rehab ward learning to walk, dress, wash, feed myself and write at the age of 31. I was only able to walk a few steps with the aid of crutches but found I was so weak I had to use a wheelchair for eight months and continued to walk with crutches and then a walking stick for another year after that.

My recovery was frustratingly and painfully slow with nothing I could do except wait for my nerves to regrow and hopefully return feeling to my feet and hands so I could walk again and just be the person I was.

Today you may look at me and think I've fully recovered but those close to me will know that I deal with the residuals of this horrible illness on a daily basis, chronic fatigue, unexplained pains, muscle weakness and dysaesthesia.

Four years ago, on 1 September 2011, I was admitted into the intensive care unit at a hospital whilst on holiday in Florida, unable to walk or feel my legs arms and face, I had no clue what was wrong with me and was totally terrified. At first the doctors thought I'd had a stroke but after many lumbar punctures, MRI scans, blood tests and CT scans I was diagnosed with a rare illness called Guillain-Barré syndrome.

I spent two weeks paralysed from the neck down in the hospital, under the care of five doctors, barely able to move and in constant and extreme pain which was kept under control with morphine. On two separate occasions during that time my heart stopped and I honestly thought I was going to die, it was quite literally touch and go whether I was to be intubated and put on a ventilator as my body was unable to breathe without support. Thankfully



Thames Path Challenge

On March 6th 2015 our mother, Yvonne Smith was admitted to hospital with a very rare condition called Gullian-Barré syndrome. Within a few days it had moved to her lungs, she was unable to breathe on her own and was moved to ICU (intensive care) where she was intubated and put on a ventilator. It was a very scary time for us all.

A few days later we thought she was starting to make progress but had a massive relapse, she aspirated whilst eating and food went on her lungs ending up with sepsis. She was so poorly, we nearly lost her and there were a few nights of not much sleep and very little hope.

This was all just before Easter weekend, but on Good Friday they felt that her infection had peaked and she was showing signs of fighting it off, we finally had a little bit of hope. Over the next two

Snowdon

This is now a lifelong illness for me and many others that live with it so to raise awareness and some funds to aid with research and support others going through GBS I am going to climb Pen Y Fan which is the highest peak in South Wales at 2,907 feet high and is an 11 mile hike. I will be doing this with the company and most likely physical support of my partner Robert on 1 September 2015 which is the four year anniversary of that awful day.

This is a huge deal for me and will be the hardest challenge I have set myself so if you can spare anything at all to spur me up that mountain I'd appreciate it more than I can ever say.

Emma Reeves



Emma has now climbed Snowdon and after completing her challenge she told us:

“ It went really well, it was pretty tough going but I really enjoyed it and I'm happy I managed to complete the challenge. I was in bed recovering for two and a half days afterwards but other than that it was great. I'm thinking of doing Snowdon again next year (watch this space) ”



weeks in ICU she made the most amazing progress and continued to make huge steps forward with her physios and after a few shaky starts she took her first steps. She finally left hospital and was moved to a residential rehabilitation unit where she moved onto walking with just a stick and then walking on her own. Over 3 months since she first went into hospital she finally came home for good. There will still be a long road to full recovery but at least she is with Dad at home.

Mum has been a total inspiration to us and we could not be prouder of how she has overcome this awful illness.

Claire Langford



Claire and her sister Emma want to raise money for GAIN not only to raise awareness of the condition but also, they hope that more research will mean quicker diagnoses and treatment. Along with six friends, they completed the Thames Path Challenge, a 25km walk on Saturday 10 September and so far have raised over £3000



The cost of fundraising

Whilst there are many ways in which we can all fundraise, a lot of us like to take part in group events and there are a large number of event organizers with no end of challenges for us to choose from. However, with all these types of events, there are costs and we would advise all our supporters to read through all the small print, agreements etc and ensure that they are fully aware of all costs involved both to themselves and sometimes the charity they are supporting. These costs may only be small, £10 or £20 but depending on the event, can run into £100's and even £1000's.

GAIN cannot be held responsible for any costs of fundraising unless by prior agreement, so please talk to us about it before you book your place.

Coming Up...

If you are planning a fundraising event, please tell us about it. Here are some we already know about:

25 October 2015 Luton Half Marathon

www.loveluton.org.uk/halfmarathon/

To support Ian Alexander please visit his JustGiving page: www.justgiving.com/Ian-Alexander6/

30 October 2015 Glow in the Park

To support Sarah Bossons please visit her JustGiving page: www.justgiving.com/Sarah-Bossons/

and some you may like to think about:

2016 Great Run Series

www.thegreatruncompany.com/

Great North (we are hoping to be allocated with GAIN charity places for this event – if you are interested, please contact us), Manchester, South, Newham London, Birmingham, Yorkshire, Birmingham 10k, Edinburgh 10 miles, Women's 10k Glasgow

2016 Great Swim Series Events

www.thegreatruncompany.com/events/great-swim/
North – Windermere, East – Suffolk, Manchester, Newham London, Scottish

2016 Big Fun Runs

www.bigfunrun.com/home

Various locations across the country

24 April 2016 Virgin London Marathon

Unfortunately we have been unsuccessful in getting Charity places for this event. If you have been lucky enough to get a place through the public ballot and want to support GAIN, we would like to hear from you

31 July 2016 Prudential RideLondon – Surrey 100

www.ridelondon.co.uk/

We have six GAIN Charity places for this cycling event – please contact fundraising@gaincharity.org.uk for further information

As 2015 draws to a close, we would like to thank all our fundraisers who have worked so hard throughout the year and raised significant amounts of money for GAIN.

We can assure you that every penny you have raised will be put to good use in helping those affected by these devastating illnesses.

Thank you

Branch & Network **NEWS**



Lancashire & Cumbria

It was another hectic meeting with 30 attendees including a couple of new faces at the quarterly Lancashire & Cumbria Branch meeting on 26 September. After an introduction by Sybil, our Chairman,

we had an interesting and amusing talk on Hearing Dogs for Deaf People from Julie. Her beautiful labrador-retriever 'Sky' stole the show by going round making friends with all, much to the delight of our youngest member, 7 year old McKauley.

Our regular Sufferers & Supporters Forum followed when we exchange experiences, questions, and tips on living with GBS & CIDP. We heard about Chantel's new speaking valve and had an interesting discussion on the adverse effect of GBS on the singing voice. Branch Secretary, Gerald, gave feedback on the GAIN AGM & Regional Day at Peterborough and several members expressed interest in attending the next GAIN Regional Day at York. We finished off with the raffle, a sale of Sybil's lovely preserves, tea and cakes and lots of happy chatting. The next meeting is our Christmas Party with Jacob's Join tea, as usual at Bilsborrow Village Hall on the A6 north of Preston, commencing at 2pm.

Scotland

Glasgow hosted 27 members of the Scottish Association of GAIN on 3 October 2015. The members attending the EGM voted in favour of changing the Branch status to a Gathering. This would give greater flexibility for members to meet up around Scotland, without the need for a committee or bank accounts. Following the EGM Professor Hugh Willison and James Babington Smith updated the members on current research and the work of the charity in a changing world. Members also had opportunity to chat with other members and share experiences.

Members were informed that on 25 June 2016 GAIN would be holding a Centenary *gain2gether* in Glasgow where there would be experts from around the world speaking on a variety of inflammatory neuropathy related topics. Details would be posted on the website and in *gain4all* once finalised.

Yorkshire

Meetings are held twice a year (March and October) at the Boothroyd Centre, Dewsbury.

Details of the March 2016 meeting will be confirmed in the next issue of *gain4all*.

Miller Fisher four years on

My story starts on New Year's Eve 2011/2012. Since before Christmas, I had had a persistent head cold and I didn't seem to be able to shake it. On this particular Saturday (31st), I had been feeling unwell; feeling that I wanted to topple over. My wife, Mary, and I went to bed, quite early for a New Year's Eve but, after a while, I felt worse and we decided to call for a paramedic. Two came and checked my heart and said that they didn't think anything was seriously wrong but took me to accident and emergency at Worcester Royal Hospital as a precaution.

Whilst there, I was seen by various medics over seven hours and part of one examination was trying to get me to walk in a straight line; without success. I was becoming less coordinated and weaker all the while. Finally, I was admitted to a ward and my wife and eldest son, Simon, returned home to rest. This was to be the last time I remember seeing them for two months even though they visited the next day and I was conscious. My vision was deteriorating and my memory fading so I cannot remember their visits. That day, unbeknown to me and whilst on the ward, I started to cough but could not clear my chest. This made me panic and the last I remember was the nurse saying that the doctor was on his way. This, I was later told was the paralysis starting.

I was given a breathing tube but, by this point, I was losing consciousness and rushed up to the HDU (High Dependency Unit). On the way there, my breathing stopped and one quick-thinking medic decided to pull out the breathing tube which allowed me a sudden rush of air and probably saved my life at this point. I was redirected to the intensive care unit.

For the next two months, I was in intensive care with the main problem being that the medics didn't really know what was wrong with me but were treating me for a stroke. I had been put into an induced coma initially but after this was stopped, I failed to wake up on my own and my family were told to prepare for the worst. On a couple of occasions it became so serious that my family were asked for permission to turn off the life support. This was refused with my daughter, Denise, particularly adamant that this was not to happen. Obviously, I owe my life to them.



Beginning my journey at Moseley Hall

Then, one day, a nurse who, expressing that she had seen something like this before, pointed out a gentleman visiting the ward. She told my younger son, Daniel, to go and have a word with him and to mention Guillain-Barré syndrome. The gentleman turned out to be a visiting medic from the Queen Elizabeth Hospital in Birmingham. He came over to my bed, examined my comatose state and said that he thought I had Miller Fisher syndrome (a variant of GBS) and that I was probably on the mend. Yet another person for whom I owe my life. From then on, things gradually started to improve; but it was to be a very slow process.

The next people I am extremely indebted to were the physiotherapists, especially one called Louise who had been treating me from my admittance. As I started to come around, the physios were able to treat me more thoroughly until I eventually started going to the hospital gym. One of the physios, I am ashamed to say that I no longer remember her name, told me that I would probably walk again, "you can usually tell!" she said. This cheered me up and gave me added determination. Again, I must thank Louise and the other physios for looking after me and for giving me hope.

Whilst all this was going on, whether it was the morphine or from simply going stir-crazy, I was having tremendous dreams and nightmares which seemed very real. They drifted across sleep into waking so that I became confused and anxious. The nurses simply took it in their stride and coped with my ramblings.

After a while, things started to improve, although getting used to the hoist proved difficult. I had my tracheotomy tube removed and was able to speak on my own for the first time in about three months. This surprised my wife when she visited as I just started chatting to her in a slow croak. Eventually, I was moved out of intensive care to a regular ward

and all the staff came to wave me off. I was only moving about fifty yards; talk about 'Mr Popular!'

All the while, I continued my physio which was becoming more strenuous but I was pleased that progress was being made. Then came the day when I was told that I was being transferred to Moseley Hall Rehabilitation Hospital and would be leaving almost immediately. After an emotional farewell to Louise and her staff, I was off.

Moseley Hall was a different sort of hospital. The priority for me was to hopefully manage to walk again. In this, I was helped by another wonderful physio, Rhianne and by a wonderful occupational therapist, Gayle. Here, my physiotherapy started with a vengeance with many one-to-one sessions. The only problem was that the hospital was further for my family to get to although my wife rarely missed a visit and other members of my family came regularly. Two of my wife's sisters came every Tuesday and you could usually hear them before you saw them but they had everyone in stitches (no pun intended!).

We had regular progress meetings with the Doctor, the nurses, physios and my family; which helped. Building my strength, straightening my foot which had curved to a 45° angle, learning to write again. But then came another significant day. Rhianne told me, after what I thought was the end of a gym session, that I was going to walk now. Absolutely gobsmacked! But we did it; with Rhianne on one side and another physio on the other. I was so pleased. From then on, things improved quite dramatically.

The rehab ward was a place where people came to get better, not to die. This adds significant strength to your motivation. It was an easy-going place in lots of ways but there were some sad cases. The patient in the next bed was a 30 year old dentist, recently married who had a stroke and finished up with Locked-in Syndrome. He was very poorly but I



Now fighting fit in 2015

believe that he has improved so much that he has written a book on his fight to get better.

Soon, Gayle the OT told me that I would be able to go home for a visit and assess how I coped. She also arranged for minor conversions to the house so that they could fit a bed downstairs in the dining room. Walking through my own front door for the first time in seven months – what a feeling! I was soon transferred to Bromsgrove Hospital for a couple of weeks until I was ready to move home permanently. Unfortunately, after showing off to my grandchildren (who had kept me going throughout the whole process) I fell and stayed in hospital for an additional two days.

I have lots of people to thank for my recovery: my family, all the hospital staff, friends. Reading the cards from well-wishers my wife had kept leaves me totally overwhelmed and tearful. I am hoping to do a walk between hospitals to raise money for charity and I am amazed that this is even a possibility from where I was at the start of 2012.

Cook the **PERFECT TURKEY**

with tips on defrosting and cooking poultry safely
Printed with permission from NHS Choices
<http://www.nhs.uk/Livewell/Healthychristmas/Pages/cooking-turkey.aspx>

Defrosting your turkey

If you buy a frozen turkey, make sure that the turkey is properly defrosted before cooking it. If it's still partially frozen, it may not cook evenly, which means that harmful bacteria could survive the cooking process.

Defrosting should be done in the fridge if possible (or somewhere cool) and separated from touching other foods, with a container large enough to catch the defrosted juices. This is important to stop cross-contamination.

To work out the defrosting time for your turkey, check the packaging for any guidance first. If there aren't any defrosting instructions, use the following times to work out roughly how long it will take to thaw your turkey.

- in a fridge at 4°C (39°F), allow about 10 to 12 hours per kg, but remember that not all fridges will be this temperature
- in a cool room (below 17.5°C, 64°F), allow approximately three to four hours per kg, or longer if the room is particularly cold
- at room temperature (about 20°C, 68°F) allow approximately two hours per kg

When your turkey is fully defrosted, put it in the fridge until you're ready to cook it. If this isn't possible, make sure you cook it immediately.

Preparing the turkey

Keep the uncooked turkey away from food that's ready to eat. If raw poultry, or other raw meat, touches or drips onto these foods, bacteria will spread and may cause food poisoning.

Bacteria can spread from raw meat and poultry to worktops, chopping boards, dishes and utensils. To keep your Christmas food safe, remember the following things:

- After touching raw poultry or other raw meat, always wash your hands with warm water and soap, and dry them thoroughly.
- There's no need to wash your turkey before you cook it. If you do, bacteria from raw poultry can splash onto worktops, dishes and other foods. Proper cooking will kill any bacteria.



- Always clean worktops, chopping boards, dishes and utensils thoroughly after they have touched raw poultry or meat.
- Never use the same chopping board for raw poultry or meat and ready-to-eat food without washing it thoroughly in warm soapy water first. If possible, use a separate chopping board just for raw meat and poultry.

Cooking your turkey

Plan your cooking time in advance to make sure you get the bird in the oven early enough to cook it thoroughly. A large turkey can take several hours to cook properly. Eating undercooked turkey (or other poultry) could cause food poisoning.

Three ways you can tell a turkey is cooked:

- the meat should be steaming hot all the way through
- none of the meat should be pink when you cut into the thickest part of the bird
- the juices should run clear when you pierce the turkey or press the thigh

If you're using a temperature probe or food thermometer, ensure that the thickest part of the bird (between the breast and the thigh) reaches at least 70°C for two minutes.

Turkey cooking times

Cook thoroughly and always check the retailer's instructions for cooking times as this will vary according to the size of the turkey. Be aware that fan-assisted ovens might cook your turkey more quickly. Cook any stuffing in a separate roasting dish, rather than inside the bird, it will cook more easily and the cooking guidelines will be more accurate.

Cover your turkey with foil during cooking and uncover for the last 30 minutes to brown the skin. To stop the meat drying out, baste it every hour during cooking.

“ 22 December is National
Defrost Your Turkey Day ”

Storing leftovers

Keep cooked meat and poultry in the fridge. If they are left out at room temperature, bacteria that causes food poisoning can grow and multiply. Cool any leftovers as quickly as possible (within one or two hours), cover them and put them in the fridge. Ideally, try to use up leftovers within 48 hours. When you're serving cold turkey, take out only as much as you're going to use and put the rest back in the fridge. Don't leave a plate of turkey or cold meats out all day, for example, on a buffet.

If you're reheating leftover turkey or other food, always make sure it's steaming hot all the way through before you eat it. Don't reheat more than once. Ideally, use leftovers within 48 hours.

Why not try this recipe?



Crispy Hoisin turkey in pancakes

Serves: 4

Prep time: 15-20 mins

Cooking time: 20-25 mins

Ingredients

1/2 tablespoon vegetable oil for greasing
 Around 300g leftover roast turkey thigh, shredded
 Half of a 240g bottle of hoisin or plum sauce
 20 Chinese pancakes (or use 8 large tortilla wraps if you can't find any)
 1 cucumber, peeled de-seeded and cut into thin strips
 4-6 spring onions, top & tailed and cut into shards
 Remaining hoisin or plum sauce to serve

Method

1. Preheat the oven to 200 C / 180 fan / gas mark 6. Lightly grease a baking sheet with the oil.
2. Mix the shredded turkey with half a bottle of hoisin sauce and spread over the baking sheet evenly.
3. Bake in the oven for around 20-25 minutes, turning once, until crispy. Serve wrapped in pancakes with cucumber, spring onion and extra hoisin sauce.

Nutritional values per portion

Energy 468.8Kcals, Protein 21.6g, Total Fat 11.2g, Saturated Fat 2.3g, Carbs 36.1g, Sugars 46.4g, Salt 2.5g, Fibre 3.3g

Pictures and recipe printed with permission from The British Turkey Information Service. Further information can be found on their website www.britishturkey.co.uk

Handheld Vegetable Peelers



When purchasing handheld peelers, consider the type of handle. A soft cushioned and slip resistant handle may make the task more comfortable and reduce pain and an enlarged handle may be easier to use if you have reduced grip.

Manipulating the peeler has been shown to be harder to manage than gripping the handle, so it also worth thinking about how the type of peeler can affect the ease of use. Most manual peelers are either:

Swivel action peelers have a blade at the end of the handle (like a knife) and can be used in multiple directions. They require more strength and rotation of the wrist than Y-shaped peelers. They suit thin-skinned vegetables like carrots.

Y-shaped peelers have a blade perpendicular to the handle. They often have swivel blades and usually have built in potato eye removers. They tend to be used for peeling fruit and vegetables with thicker skins. Y-shaped peelers do not require rotation of the wrist so tend to be easier to use if you experience pain or reduced strength in the wrist.

Either of these types of peelers is readily available on the high street but the ones included here have features such as wide or padded handles which can enhance and facilitate grip.

For further information on equipment for preparing and cooking food, including details of suppliers, please visit the Living Made Easy website www.livingmadeeasy.org.uk/

(You could avoid peeling vegetables at all by cooking/roasting or baking them in their skins)



HINTS AND

MOTORING

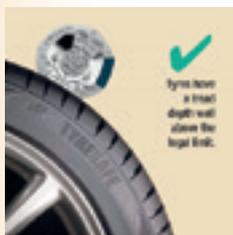


Prepare your vehicle for Winter driving

It is important to make sure your vehicle is well maintained all year round but vital during the Winter months

Top Tips

- Check your battery
- Ensure you have sufficient anti-freeze in the coolant
- Check the oil
- Are the windscreen wiper blades in good condition?
- Make sure you have enough screenwash (with protection for lower temperatures)
- Check tyre condition – look for damage such as splits or bulges, make sure there is adequate tread and pressures are correct
- Tyres should have a minimum depth of 1.6mm, but ideally 2mm. To check tyre tread depth you can use a 20p piece as demonstrated below:



Items to have in the car

Be prepared for the unexpected and put together an emergency kit to carry in the car

Top Tips

- Charger for your mobile phone
- Jump start cables
- Reflective warning sign
- Ice scraper and de-icer
- Torch
- Extra blankets/warm clothes
- Food and hot drinks
- First aid kit
- A shovel

Before setting off

Before setting off it's worth spending some time planning your route and making a few more checks

Top Tips

- Check local and national news for severe weather reports
- Clear snow or ice off your vehicle
- Check lights are working
- Have you enough fuel to get to your destination?
- Give yourself extra time when travelling in bad weather

When driving through snow and ice

Top Tips

- Use the highest gear possible to avoid wheel spin, but taking care not to let your speed creep up
- Brake gently to avoid locking the wheels. Get into a low gear earlier than normal and allow the speed of the vehicle to fall gradually
- Take corners very slowly and steer gently and steadily to avoid skidding. Never brake if the vehicle skids, instead, ease off the accelerator and steer slightly into the direction of the skid until you gain control
- If stuck in snow, do not spin the wheels or rev the vehicle, as this will dig the vehicle further in. Instead, put the vehicle into as high a gear as possible and slowly manoeuvre the vehicle lightly forwards and backwards to gently creep out
- If you are stuck fast, stay in the vehicle unless help is visible within 100 yards. Do not abandon your vehicle as this can hold up rescue vehicles

TIPS

When driving in rain and heavy floods

- Rain and floods: follow these tips if you get caught driving in heavy rain and floods:
- Keep well back from the vehicle in front as the rain and spray makes it difficult to see and be seen
- Look out for steering becoming unresponsive, which can happen if water prevents the tyres from gripping. If this occurs, ease off the accelerator and gradually slow down. If possible, pull over somewhere safe until the rain stops and the water drains away
- Never attempt to cross a flooded road if you are unsure how deep it is; only cross if you can see the road through the water. Apart from potential damage, many vehicles require only two feet of water to float
- If driving on a flooded road, stay in first gear with the engine speed high and drive very slowly. Do not drive through floodwater if a vehicle is coming the other way. If possible, drive in the middle of the road to avoid deeper water near the kerb.
- Test brakes immediately after driving through water by driving slowly over a flat surface and pressing the brakes gently. Warn passengers first.

Our thanks to Brake for this important information
www.brake.org.uk

Notifying the DVLA

The following information is taken from the GOV.UK website;

www.gov.uk/guillain-barré-syndrome-and-driving

Guillain-Barré syndrome and driving

You must tell DVLA if you have Guillain-Barré syndrome [also applies to CIDP and associated inflammatory / peripheral neuropathies]

You can be fined up to £1,000 if you don't tell DVLA about a medical condition that affects your driving. If you're involved in an accident, you may be prosecuted.

Car, motorcycle, bus, coach or lorry licence – tell them about it

Medical conditions, disabilities and driving

Further information is available:

Telling DVLA about a medical condition or disability

www.gov.uk/driving-medical-conditions

What happens after you tell DVLA

www.gov.uk/driving-medical-conditions/what-happens-after-you-tell-dvla

What the DVLA will decide

www.gov.uk/driving-medical-conditions/what-the-dvla-will-decide

Renewing or re-applying for your licence

www.gov.uk/driving-medical-conditions/renewing-or-reapplying-for-your-licence

Reapply for a driving licence following a medical condition

www.gov.uk/reapply-driving-licence-medical-condition





Top tips for planting your tulip bulbs this Autumn

Now is a great time to be planting your spring flowering bulbs. Here, Adrian Nind, Managing Director at Bakker Spalding Garden Company, provides five top tips for your autumn gardening.

1. Preparation is key

The first step is to remove weeds and incorporate lots of compost or other organic matter when planting your bulbs. Bulbs grown in pots need good drainage so put plenty of pot shards in the bottom and use well-drained compost.

2. Select your bulbs early

With so many stunning spring flowers to choose from,

selecting your flower bulbs is something you should do at an early stage. A recent survey we conducted revealed that the favourite colour plants here in the UK are red (23.5%) followed by purple (17.6%). We've seen a great deal of interest in our wide variety of tulips this year, including the 'Exquisit' tulip which resembles a double peony and the 'Tropical Wave' tulip which has a fantastic double yellow goblet.

3. Have your bulbs delivered just before you intend to plant them

Bulbs should be in optimum condition for planting. If you can't plant them straight away, unpack the bulbs as soon as you can. Place them in a dry, dark place under 20°C and open the packaging so that air can circulate.

4. Plant your bulbs correctly

Bulbs have very particular planting requirements, and should be planted in holes three to four times as deep as the bulb itself. Plant your bulbs in groups of at least six to ensure optimum results, and if you are unsure on which way the bulb should go into the soil, plant the bulb on its side: its stem will find its own way up to the surface!

5. Don't forget to prepare your bulbs for next year!

We recommend feeding your tulip bulbs immediately after flowering – this gives the bulb time to store enough nutrients to ensure profuse flowering the following spring.

For more hints and tips, visit their website: www.spaldingbulb.co.uk

Bakker Spalding
Garden Company



Bulb Planter

Particularly recommended for:

- One Hand
- Weak Grip
- Blind and partially sighted

This tool is useful for creating small planting holes for bulbs and plants. Push the tapered body of the planter into the ground and extract a plug of soil by squeezing the handle. The holes made by a bulb planter are around 60mm wide and up to 100mm deep. This tool is easier to use for planting small plants and bulbs than a trowel.

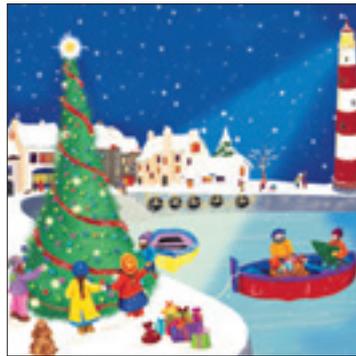
There are long handled versions of bulb planters, which you could use sitting down or to reduce bending, but you will need good balance and a strong arm to use them and they tend to clog up if the soil is damp.

Having a disability does not necessarily mean we cannot continue to enjoy the pleasure of gardening. For further information, useful hints and tips and details of the equipment and tools which will be particularly helpful visit: www.thrive.org.uk and www.carryongardening.org.uk

Our thanks to Thrive for the information and picture above.



1. Santa's New Hat (with foil)
81 x 200mm
£4.25 for 10 cards



2. Home in Time for Christmas
121 x 121mm
£3.75 for 10 cards



3. Frosty Tree
(with flitter)
81 x 200mm
£4.25 for 10 cards



5. Floral Wreath (with silver foil)
121 x 121mm
£3.75 for 10 cards



6. Decorative Partridge
140 x 140mm
£4.25 for 10 cards



4. Three Ships
126 x 126mm
£3.75 for 10 cards



8. Bobbing Robins
(with red foil)
200 x 81mm
£4.25 for 10 cards



7. Christmas Fun
126 x 126mm
£3.75 for 10 cards

A variety
of 20 cards
from the 2015
selection

10. Variety Pack
Various sizes
£7.45 for 20 cards



9. Skating Santa
140 x 140mm
£4.25 for 10 cards

The Greeting inside these cards reads:
*With all good wishes
For Christmas and the New Year*

2015 Christmas Card Order Form

Please detach this order form and send together with payment to:
GAIN, Woodholme House, Station Road, Heckington, Sleaford, Lincolnshire NG34 9JH



OR order ONLINE through our website: www.gaincharity.org.uk and click on the **SHOP** link

Card Ref.	Title	Qty per pack	Price per pack	No. of packs	Total Price per line £
1	Santa's New Hat (with foil)	10	£4.25		
2	Home in Time for Christmas	10	£3.75		
3	Frosty Tree (with flitter)	10	£4.25		
4	Three Ships	10	£3.75		
5	Floral Wreath (with silver foil)	10	£3.75		
6	Decorative Partridge	10	£4.25		
7	Christmas Fun	10	£3.75		
8	Bobbing Robins (with red foil)	10	£4.25		
9	Skating Santa	10	£4.25		
10	Variety Pack	20	£7.45		

Subtotal	
Post & Packaging	
Donation – thank you	
TOTAL price	£

Postage and Packaging Costs		
UK	Europe	Rest of the World
£3.50	£5.75	£9.90

We hold a large stock of cards, but some designs sell out early. Should this occur, please select box and tick below to advise what should be done with balance of money.

Send alternative cards, similarly priced Donation to us Refund

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I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008

Print name	Signature	Date
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Payment by cheque

Cheque enclosed for £ (Sterling only) payable to: **GAIN**

DELIVERY DETAILS

Name

Address

Postcode Telephone



Useful links

Age UK	www.ageuk.org.uk/ Helpline 0800 169 6565	Information, advice and support for older people
Carers Trust	www.carers.org/ Tel: 0844 800 4361	Support and services for carers
Citizens Advice Bureau	www.citizensadvice.org.uk/ Tel. (Wales) 08444 77 20 20 Tel. (England) 08444 111 444 www.adviceguide.org.uk/	Free independent and confidential advice including fact sheets, sample letters and budget calculator
Cochrane Library	www.thecochranelibrary.com/	Independent high quality evidence for health care decision making
Department Health IVIg	www.ivig.nhs.uk/	A resource to healthcare providers to understand the Demand Management Programme for Immunoglobulin and access guidance and materials to ensure its effective implementation
Direct Gov	www.gov.uk/	Information on benefits, DVLA etc
Disabled Living Foundation	www.dlf.org.uk Helpline 0300 999 0004	Impartial advice, information and training on daily living aids
Disability Rights UK	www.disabilityrights.org/	Promoting independent living for disabled people
Expert Patients Programme	www.expertpatients.co.uk www.wales.nhs.uk/sites3/home.cfm?orgid=537	A self-management programme for anyone over 18 with a long term health condition to help you learn
ICU Support Network (Reading)	www.readingicusupport.co.uk	Support for all patients and relatives during the patient's time in ICU as well as after their transfer from the unit/or discharge from the Royal Berkshire Hospital
James Lind Alliance	www.lindalliance.org/	A non-profit making initiative which brings patients, carers and clinicians together to identify and prioritise the top 10 uncertainties, or 'unanswered questions', about the effects of treatments that they agree are most important
Listening Books	www.listening-books.org.uk	A service for those whose illness or disability makes it difficult or impossible to hold or concentrate on reading a book
Neuro News	www.neuro-news.co.uk	Community hub for information on neurological conditions
Neurological Alliance	www.neural.org.uk/	The only collective voice for more than 70 national and regional brain and spine organisations working together to make life better for 10 million children, young people and adults in England with a neurological condition
NHS Complaints Advocacy	www.nhscomplaintsadvocacy.org	The NHS Complaints Advocacy Service is a free and independent service that can help you make a complaint about a National Health Service (NHS)
Pubmed	www.ncbi.nlm.nih.gov/pubmed/	Citations for biomedical literature from MEDLINE, life science journals, and online books
Scope/DIAL	www.scope.org.uk/dial	Local disability information and advice
Silverline	www.thesilverline.org.uk/	Confidential helpline providing information, friendship and advice to older people, open 24 hours a day
Turn2us	www.turn2us.org.uk/	Helping people to access welfare benefits, charitable grants and other financial help

The Charity receives no Government or Lottery funding and relies solely on charitable donations which can be made online through our website or forwarded to the office address.

Thank you

In memoriam

A donation to GAIN is a special way of remembering the life of a relative or friend.

www.gaincharity.org.uk