Cambridgeshire Branch

Spring 2018

5 7



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A special showing of the film "The Theory of Everything" has been screened by a Cambridge cinema to raise funds for the branch.

The Light Cinema based at the Cambridge Leisure Park will be donating all the ticket proceeds from the screening to us.

Based on the memoir **Travelling to Infinity: My Life with Stephen,** by Jane Hawking, the film was shown as a celebration of Professor Stephen Hawking's life and incredible legacy.

The generous gesture came unexpectedly as the result of an email to Cynthia from the cinema advising they would like to make a donation to an organisation that had links with Professor Hawking. Cynthia explained the work and aims of the Association and suggested our MNDA branch would like to be involved. As a result, we were given this great opportunity both to raise awareness of MND and a welcome boost to our funds. The time-frame was extremely tight as the cinema wished to have the film evening within two weeks from initial contact.

Hayley Croot, Business Manager for The Light Cinema said Professor Stephen Hawking was a much valued customer of The Light Cinema over the years. "We really wanted to pay tribute to his life and achievements."

Cynthia said: "We were honoured Professor Stephen Hawking was a Patron of the MND Association since 2008. Throughout his inspirational life he played a vital role in raising awareness of motor neurone disease locally and around the world. We were delighted to be chosen by The Light Cinema as a local charity to receive all the funding from this screening". On the evening of Thursday 5 April, Maire, Simon and Fred went along to represent the branch and promote the MNDA and the Cambridgeshire Branch.

A short MNDA video was shown at the start of the evening in place of the usual adverts followed by Simon giving a short talk on MND before the main film 'The Theory of Everything' was shown to the 58 people who attended.

Before, during and after the film, Maire, Simon and Fred collected donations from people who were walking through the foyer.

The Cambridgeshire Branch will be receiving the entrance fee of £10 per ticket (£580) from the Light Cinema and collected a further £108 in buckets, a total of £688.

Cynthia George: Chair



ANNUAL GENERAL MEETING: 21 March 2018

The Annual General Meeting took place on 21 March 2018 at Hemingford Abbots Village Hall. It was attended by 40 people: our Speaker, Committee, AV/CSN, Speaker, Committee, members and friends and apologies were received from 33 people.

Cynthia George, Chair: welcomed Dr Rhys Roberts, Consultant Neurologist at the Cambridge MND Care Centre who would be presenting a talk after lunch. She also welcomed everyone else to the AGM, and thanked the Village Hall Committee for allowing the use of the delightful hall. She hoped it would be an interesting day and that everyone would enjoy the presentation by Dr Roberts, and the delicious buffet lunch provided by Christine and Andrew Norton and their daughter Jane Copeman.

AGM Minutes for 2017: There were no issues arising. John Morren proposed that the Minutes should be adopted and Keith Scrase seconded. The Minutes were agreed as a true record.

Chair's Report: "It has been another very busy twelve months and one in which I feel we have been very successful in promoting the MND cause and Fundraising. Quite a challenging year but one that we have come through stronger and are even more determined to find a cure for this dreadful illness.

As we all know, it can be a devastating and traumatic time coming to terms with the diagnosis of MND, not knowing what the future may hold, something none of us knows. I hope it helps, if only in some small way, to know we have the MND Care Centre, the Branch and Association all there to help and give advice and information. It goes without saying that this includes the spouse, carer and family – you come as a "package" and need not be "sailing solo" in fearful unknown waters.

Research is a top priority for the Association with all of us remaining optimistic that in the not too distant future a cure will be found. There is an enormous amount of work going on in the background which most of us will not be aware of and even if we were, would not fully understand. I continue often to feel overwhelmed with the vast amount of information to digest and understand.

Here is a little information about the Branch for those of you who have recently joined us:

Cambridgeshire Branch

- We were founded in 1987

- We cover the whole of Cambridgeshire and can offer support to those living just over the county boundaries

- We have 10 committee members; 6 AVs/CSN. All are volunteers, some undertaking a dual role.

- We represent the MND Association at a local level and focus on providing support to those living with MND and their families/carers by way of
 - Social Monthly Afternoons
 - Fundraising
 - Raising awareness
 - Campaigning

All the work would not be possible without the effort put in by our branch committee members, AVs and CSN. We are all volunteers giving many hours of our time and we do this because we WANT to, but I would like personally to thank all of them for their devotion which enables the Branch to run like clock-work and makes my position as Chair that much easier.

We are of course ably supported by MNDA staff, especially allocated to the Eastern area: the Regional Care Development Advisors, Liz Cooper and Lindsay Goward; our Volunteering Development Co-ordinator, Neil Penson, and Regional Fundraiser, Roger Widdecombe.

Cynthia George gave delegates the names and the roles of the current committee members:

Maire Collins, Branch Secretary: Our Secretary for many years, in fact 13 – I should say lucky 13 not unlucky 13. She has a wealth of knowledge, is so organised and keeps us all on our toes – that includes me as well. She also finds time to help fundraise.

Melanie White, Branch Treasurer: Our Treasurer who does a fantastic job for us in keeping our "financial house" in order. She has to work within the criteria set-down by the Association which is not always an easy task. She carries out the work extremely efficiently in

spite of her family commitments and working full-time.

John Morren, Vice Chair: My thanks to him for serving as Vice-Chair and the support he gives as a committee member.

Simon Crooke, Fundraising Co-ordinator and *Financial Support Co-ordinator*: Simon's enthusiasm never wanes and his energy levels are phenomenal!

Anthony Flynn, Newsletter Editor: A big thank you to Anthony for another year of excellent work in producing our branch newsletter. I feel the newsletter gives a professional image and I hope you agree provides an interesting and informative read.

David Griffiths, Webmaster: Our local Cambridgeshire Branch Website is kept updated on a regular basis by David. A big thank you to him for taking this on board (www.mndassociation.org/cambridgeshire).

Veronica Angus, Chris Glover and Pam Wilkie: What can I say about these three ladies! Firstly, they are very loyal committee members always willing to help out and provide a great deal of knowledge and support not only at our committee meetings but at the social afternoon Get-Togethers and in general.

AVs and CSN: As part of the team there are also the AVs and CSN, some of whom were present.

CSN
Brenda Parkes

Unfortunately, Ann Porter, a CSN and AVC stood down during the year and the AVC role remains vacant.

Volunteer: We have a new volunteer, Steve Gedney, who has come on board to help out.

Campaigns Volunteer: At last year's Branch AGM I was able to announce the Association had appointed Daniel Emery as the new Campaigns Volunteer Co-ordinator. Regrettably he has very recently stood down from this role due to personal circumstances. I would like to thank him for all his work on campaigning – he was the person who was instrumental in getting Peterborough City Council to adopt the MNDA Charter which I am sure will be most helpful in that part of the county. I would like to record my thanks to him for all his efforts and wish him and his family all the best for the future.

My constant goal is that we all work as a team. Thanks to everyone's support and hard work I believe we are achieving this.

Fundraising: I happily leave fundraising to Simon to give you an overview a little later on with his presentation but I would like to thank everyone who fundraises for us. This has meant we continue to be able to support requests from those living with MND. Our year- end balance is £9,869.50 in our Branch General Fund to start this current financial year. We are once again fortunate to have good reserves in our Restricted Fund balances to assist with payment of Funding Requests. Without the generous fundraising donations, and the restricted funds, it is quite clear that we would struggle to cope with the financial requests that we receive.

Adoption of accounts: John Morren proposed that the accounts be adopted and Val Kay seconded. Members accepted the accounts as correct.

Election of Branch Committee: Cynthia George reminded delegates that only members may vote; she suggested that as all the committee were happy to stand again that an *en bloc* vote would be appropriate if everyone agreed.

The current Officers and their responsibilities are as follows:

Cynthia George - Chair and Branch Contact John Morren - Vice-Chair Maire Collins - Secretary Melanie White - Treasurer

Simon Crooke *Proposed* and Keith Scrase *Seconded* that the current Officers be adopted.

Current	Committee	members	and	their
responsil	oilities:			
Veronica	Angus -	Support		

Simon Crooke -

Anthony Flynn -Chris Glover -David Griffiths -Pam Wilkie - Support Fundraising and Financial Support Newsletter Editor AV and Support Webmaster AV and Support Fred Smith *Proposed* and Sue Hallifax *Seconded* that the current Committee members be adopted.

This has meant we continue to be able to support requests from those living with MND and their families to supply items not available by statutory services or to buy or hire equipment to make lives that much easier.

Volunteers Award: It is a pleasure to let you know that last year the Peterborough Council for Volunteers presented Simon Crooke with a Volunteers Award in recognition of his fundraising work for the Branch and the tremendous effort he put in to help promote and raise funds during the year. We were one of the Peterborough Mayor's charities.

Get-Togethers: We continue with our regular monthly social Get-Togethers at three venues around the county. The Cambridge one on the Scotsdales Garden Centre site in Great Shelford continues to be the most popular. These Get-Togethers are for you to come and chat between yourselves and enjoy a relaxing afternoon. We sometimes have a speaker but they are run for you, our members and families to come and socialise, gain information or helpful hints from each other.

We always end the year with a light-hearted Christmas-themed afternoon. The hot mulled non-alcoholic punch seems to go down well on arrival and gets the afternoon off to a bright start.

I close with a thank you once again to everyone for supporting me over the last year. It's been a great year for fund-raising; for seeing the profile of our Association grow in strength and for our volunteers' teamwork, producing everincreasing support throughout our region as we move towards our greatest goal of all – finding a cure for MND. We will continue our fight to achieve this." (Cynthia George, Chair)

Presentation of accounts: Report from Melanie White (Treasurer) read by Maire Collins: Income for the last financial year was a spectacular £55,097.33, with expenditure amounting to £46,653.34. Fundraising activities and Corporate donations made up 64% of our income this year. Expenditure on "Care and Support was 50% of the overall total spend and included payments for such things as Young Persons Grants, Carers Grants, alternative therapies, closomats, stairlifts, hoists, respite care and house adaptations to name but a few.

The year-end restricted fund balances total £30,115.96. Expenditure from the restricted funds was £13,485.68 and is included in the above total expenditure.

Fundraising report: Simon Crooke presented the following report with illustrations on screen:

Once again we have had a great year fundraising and for that we have to thank all of our fundraisers as without them we as a Committee couldn't operate in order to help people living with MND.

There were various events around the county including concerts by the Littleport choir and the RAF bands which raised £400 and £1500. We also had our Grafham walk and all the excellent work done by the Cottenham Fundraising Group. Thanks to Sarah Bates we had 11 cyclists who rode 172 miles from Morecambe to Bridlington. Our cyclists enjoyed a fantastic three days and a total amount of £1600 was raised. Our annual bucket collections at railwav stations in Cambridgeshire raised over £2000. The amount of cakes and tea parties held was fantastic and every penny raised will go to help people living with MND.

Pam Wilkie held her annual Cream Tea in her lovely warm and sunny garden. There was music from the Hilton Ukulele Group, and Sue Hallifax and her partner John sang together.

The joint Cambridge Building Society and Cambridge News 'Cash in the Community' annual event took place with Cynthia George and Maire Collins being presented with a cheque for £862.

Future events:

Dressdown Day: Simon had written to all secondary schools in the area about holding a 'Dressdown Day' on Friday 15 June, with each student paying £1 to take part.

National Three Peaks Challenge: This year we will be attempting the challenge during the last May bank holiday. If you wish to take part please email Simon at simoncrooke@aol.com.

Once again many, many thanks to all our Fundraisers for all they do. Every penny that is raised goes to help everyone living with MND.

Again, a big thank you for all your fundraising and please continue as we as a committee really do appreciate all your hard work

Cottenham Fundraising Group: Andrew Norton presented Cynthia George with a cheque for £4,500 which had been raised by the Cottenham Fundraising Group through selling cards (and favours for Easter and Christmas) mainly at Addenbrookes Hospital Outpatients Hall, and holding lunches within the village; this money had been raised by its trustees and other helpers.

MNDA Long Service Awards: Maire Collins explained that the Association liked to award volunteers with a Certificate and Badge after 5, 10, 15 years respectively, etc. The badges were rather like the Olympics/Marathon, awarding bronze, silver and gold. She asked Dr Rhys Roberts to present a certificate and bronze award to David Griffiths who had been a Committee member for five years working very hard setting up our website, and more recently the Facebook Page. She then asked that Cynthia George be awarded her certificate and silver badge after serving 10 years, firstly as branch contact but for the last two years as Chair.

AGM Speaker: Dr Rhys Roberts

The Presentation was given by Dr Rhys Roberts, Consultant Neurologist at the



MND Clinic, Addenbrookes Hospital entitled "The Cambridge MND Care Centre - an update on our move". Dr Roberts explained that he would talk about pre and post 2005 saying that Joanna Sasson and Dr Allen set up the Centre to include other health professionals such as: Dietitian, Speech Therapist, etc. whose services were adapted to individual needs. Cases were compared pre and post 2005. They then looked at 2009/10 and the epic failure of the paperless system which became a challenge for Helen Copsey.

Since the Care Centre was set-up patient information on family members who may or may not have been diagnosed with MND has been improved. Joanna Sasson and Helen Copsey asked questions of MND patients such as 'Did you receive answers you could understand? How long after your first appointment time did the appointment start? What is your overall opinion of the service?

Dr Roberts showed various tables and graphs illustrating how treatment had improved and how the improved collection of data would be used in research.

Addenbrookes Hospital has grown into a massive Centre of Bio-Medical expertise over the years which shortly will include Papworth Hospital.

There is still not enough room on the site so in 2017 the MND Care Centre moved to the new

Arthur Rank Hospice at Shelford Bottom (see picture right). At this site there is level access and suitable parking near the building. The Centre was purpose built with four clinic rooms



and a much improved waiting area. Now the Clinic has relocated, the Care Centre staff are currently repeating the patient feedback study and have been receiving lots of information. There are 11 staff members with varying expertise and a Research Nurse is about to be appointed. Referrals to the Care Centre now come from a radius of up to 60 miles.

There followed a series of questions put to Dr Roberts who was able to reply satisfactorily to the majority.

Vote of thanks: David Griffiths thanked Rhys for giving up his time to come and give us such an interesting presentation and also for all the support he and his staff give to people living with MND.

Maire Collins, Secretary

Get-togethers

Thursday 19th October David Rayner Building, Cambridge

Members you really did turn out in large numbers for this afternoon at the David Rayner Building on the Scotsdales Garden Centre site. It was a magnificent attendance and a pleasure to need to keep finding more space and chairs. It was great to see the MND Care Centre staff – Dr Rhys Roberts, Victoria Edwards and Louise Boardman - there as well.

We were delighted to have Sally Light, Chief Executive of the MND Association, with us for the afternoon. Her talk was titled "The MND Association: Going further together, with an update on recent progress". Sally gave an interesting and informed presentation with the vision being "A world free from MND". She said the Association funds research, seeks to improve care and provide support, and campaign to raise awareness.

Research: Sally gave examples of research to help people living with MND and to find the causes:

- Sheffield Snood
- Project MINE
- Biomarkers
- Drug Trials
- The MND Register (a definitive record of everyone who has MND)

Improving care and support provided by other professionals:

- Funding Care Centres
- NICE Guidelines
- Education: training for health care professionals

Campaigning to raise awareness:

 Campaigning on national and local issues including through campaign contacts. Fifty-one councils have signed the Charter so far.

Sally's final comments were there is still "lots to do":

- Translate understanding into treatment.
- Multidisciplinary care available to all.
- Improve access to specialist equipment.
- Access local council services and benefits.
- Continue to raise awareness.
- Fundraising in an ever-changing environment.

The above gives a very brief resume of Sally's presentation following which she answered questions put to her. She went away with some thoughts and comments from you a couple of which were new to her.

Following this Sally mingled amongst members while teas and coffees were taken round. Another full and enjoyable afternoon.





Cynthia George

Thursday 7th December 2017 David Rayner Building

The David Rayner Building had a festive look for the Christmas party afternoon with many of you making the journey to the garden centre, more than thirty in total. The non-alcoholic punch served as people arrived was complemented by delicious festive food.

The merry note to proceedings was backed by some super seasonal singing from Association Visitor Sue Hallifax and John, accompanying their songs on guitar.

The light-hearted popular quizzes produced by Chris and Geoff were a time for concentration and deep thought.

During the afternoon small gifts were handed out to members with a red poinsettia presented to the party-goers as they left for home. All going home with a smile having enjoyed a relaxed, happy and friendly time.

Wednesday 3rd January Huntingdon MS Therapy Centre

At Huntingdon on 3rd January only a small number braved the winter weather but some new faces gave the occasion a lift despite the absence of Chair Cynthia – stuck at home with a virus!

Wednesday 15th February David Rayner Building, Cambridge

Another well attended afternoon at this popular venue with everyone chatting easily and mingling.

The highlight of this event was a talk by Dr Daniel Ives whose research is extending to include investigating whether defective mitochondria are linked to Motor Neurone Disease. Mitochondria are miniature power stations in the body that produce the majority of our energy and defective mitochondria have been tentatively linked to MND by researchers.

Dr Daniel Ives has previously studied Parkinson's disease and identified a difference between the saliva of individuals with Parkinson's and their unaffected relatives. This difference suggests that individuals with Parkinson's disease have a fault in their mitochondria.

Maintaining high energy levels is crucial to the survival of motor neurones which are lost during Motor Neurone Disease. Faulty mitochondria have also been linked previously to both rare and common forms of MND. Therefore, he would like to determine whether individuals with MND do in fact have faulty mitochondria by collecting saliva from individuals with MND and their unaffected relatives. If you are over the age of 50 years, have no family history of MND, have an unaffected maternal sibling, parent or child and are interested in participating in this study please contact d.ives@herts.ac.uk.

Cynthia George

Advance Date for Diaries

Open Garden Sunday 24th June 2018

Pam Wilkie has very kindly decided once again to open her garden in aid of the MNDA. This will be on the afternoon of Sunday 24th June. Strawberries, scones and cream with other delicious goodies will be served with a cup of tea/coffee or cold drink. There will be live music, a raffle and lots more.

This is "hot off the press" news; further details will be available shortly. Please note the date in your diary.

Cynthia George

Employment Support Allowance Campaign

What is Employment Support Allowance (ESA): it is an allowance that may be payable to those who have an illness, health condition or disability that makes it difficult or impossible to work.

In February, the Association met with the Minister for Disabled People, Health and Work and handed over the open letter signed by 8,000 supporters to show the strength of public support behind scrapping benefits reassessments for people with MND.

Our aim is to stop people living with MND having to go through reassessments in order to receive this benefit. Through the Association's campaigning work considerable success has been achieved and since October 2017 no one with MND claiming Support Group ESA for the first time will have to have a reassessment.

It is regrettable the new rules on ESA reassessment were not applied to people already claiming ESA and as things currently stand they will have to have one more paper-based reassessment before they are given

exemption. This situation is unacceptable and causes unnecessary anxiety and stress for those concerned. If you are called for reassessment then the Association would like to hear from you and can be contacted by email on campaigns@mndassociation.org.

Cynthia George

Data Protection (General Data Protection Regulations - GDPR)

New Government rules on Data Protection will come into effect from 25 May 2018.

We have heard very recently from National Office that for the Association and consequently us as a branch to adhere to these new Government Regulations we are obliged to contact every individual on our Branch Database to ask that everyone agrees we may keep the contact details we have. The information we hold is name, address, telephone number, email address and where applicable, spouse or partner's name.

If we do not get agreement by 25 May we will have to remove those individuals from our database and lose the details. Therefore, we will be sending out letters to you all in the near future.

It will be most helpful to us if following receipt of the document you sign and return your replies immediately or as soon as possible. This will involve a lot of time so your help in this will be appreciated.

Maire Collins: Secretary; Cynthia George: Chair

Easyfundraising.org

Easyfundraising.org is a great way to raise money just by shopping online. You don't pay anything extra. All you need to do is go the easyfundraising website, click through to the retailer you want to buy from and make your purchase.

The price will be exactly the same and the retailer will give you a cash reward that you can turn into a donation. Easyfundraising collect this and send it on at no extra cost.

Visit easyfundraising.org and find out more.

How to set up a donation page

A quick reminder that if you're setting up a charity event and you want to generate as much money as possible for your cause, then you may look to set up a donation page.

So, is there a difference with which one you should choose? Well on the face of it no there isn't as they all do the same job - they promote your event and take donations from people who want to support you.

However, while most do make a charge for their services, for example Just Giving and Virgin Money, there is one that doesn't charge called My Donate. This is a BT service and all the money donated via my donate goes to your good cause.

So, when setting up a donate page please think about the costs charged and maybe you might be tempted to go for one that doesn't

Simon Crooke Fundraising Co-ordinator

Financial Support/Grants available for people affected by MND

TheMotorNeuroneDiseaseAssociation/Branchmay be able to offer somefinancial support to help with:

- funding equipment and services that people with MND have been assessed as needing
- funding for children and young people affected by MND
- non-paid carers supporting someone living with MND
- improving quality of life for someone living with MND.

This is not in place of any statutory funding that should be available but when equipment may not be immediately available from the NHS or statutory services we may be able to help. We can also assist with obtaining statutory funding or funding from other charitable organisations.

Who can apply for grants? Most of our grants can be applied for by the person living with MND, a family member, volunteer or health and social care professional. There is only one, the MND Support (Care) Grant which **must** be applied for by a health and social care professional.

Young Person's Grant: A grant for young people aged 18 or under who are affected by MND to help support them in their day-to-day life. This may be a contribution for instance towards after school activities, a holiday, a personal item for their bedroom.

If you are a parent or carer of someone aged 18 or under or even know someone in this age group who is affected by MND who may benefit from a grant of up to £250, within a rolling twelve-month period, then an application form is available online.

Carer's Grant: A grant to an unpaid carer aged 18 or over who is caring for someone living with MND may be available within a rolling twelvemonth period. The aim of the grant is to allow non-paid carers to take a break from their caring duties, i.e., this may be a pamper day, a short break etc.

Quality of Life Grant: This grant is to help improve the quality of life of a person with MND that does not require an assessment.

MND Support (Care) Grant: A grant which may be available to anyone living with MND. It can be used only once an assessment has been made and all statutory funding options have been explored. The following procedure needs to be followed:

- Assessment is made by a qualified health or social care professional (HSCP).
- 2. Statutory funding should be sought at this point (we can assist and offer advice).
- If funding is not available or is not timely, the HSCP should complete the Support (Care) Grant application form and send it to Support Services.
- 4. On receipt of the application the request and the supporting evidence will be reviewed.
- 5. A decision on the amount to be offered will be communicated to the applicant. Please note this is unlikely to be the full cost of a provision.

Who can apply for this grant? This has to come through Health and Social Care professionals.

Other funding available: As well as grants available from the Association there are a number of other organisations that may offer financial support, details are available on the Association's website, www.mndassociation.org_

Further information or to discuss any of the above please contact Simon Crooke, Financial Co-ordinator, Cambridgeshire Branch: email: cambridge@mndassociation.org OR the Association by email, support.services@mndassociation.org telephone 01604 611802.

Supporting families affected by MND in Cambridgeshire

In Cambridgeshire we are fortunate to have a small team of dedicated 'care volunteers' who support families affected by MND directly either by e-mail, phone or visiting.

Our two key 'care' roles include the Association Visitor who will support the family on the journey with MND and the Care Service Navigator who helps people affected by MND to access and navigate services from health, social care and voluntary organisations.

We provide robust training and ongoing support for the role. In Cambridgeshire the (Regional Care Development Advisers (RCDAs), AV and CSN team meet every 6-8 weeks where information is shared and peer support obtained for the respective roles.

In addition, the Volunteering Team is developing more flexible and short term roles as part of our STRONG campaign.

To find out more or to get involved please visit our webpages: www.mndassociation.org/getinvolved/volunteering

Liz Cooper & Lindsay Goward

Regional Care Development Advisers for East Anglia Motor Neurone Disease Association Tel: 03453751827/9 eastangliarcda@mndassociation.org

MND Association volunteering

motor neurone disease

association



The MND Association is supported by more than 3,000 volunteers across a range of different roles. Volunteers play an important part in helping us to ensure that people with MND and their families receive the support and services they need.

Could you give your time to support people with MND?

We have volunteering opportunities to suit a range of different skill sets and time commitments.

To find out more about the different ways you can give your time to make a difference, visit our website, contact us on 0345 6044 150 or email volunteering@mndassociation.org

For support and further information: MND Connect 03457 626262

www.mndassociation.org

Cambridgeshire branch

contacts

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Future Get-Togethers... Dates of Get-Togethers in 2018

Wed 16 May Thurs 14 June Wed 11 July Wed 12 Sept Thurs 11 October Wed 14 November Thurs 6 Dec Huntingdon Gt Shelford Peterborough Huntingdon Gt Shelford Peterborough Gt Shelford