

Fundraising Information Pack



With handy hints & tips to help you make the most of your Fundraising.



Contents:

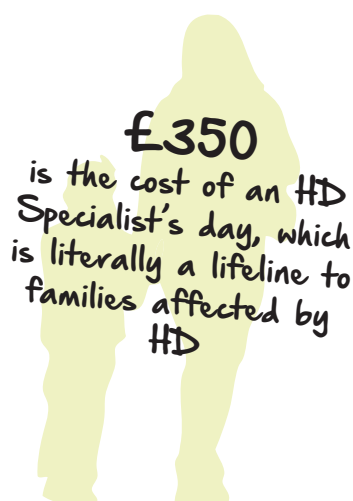
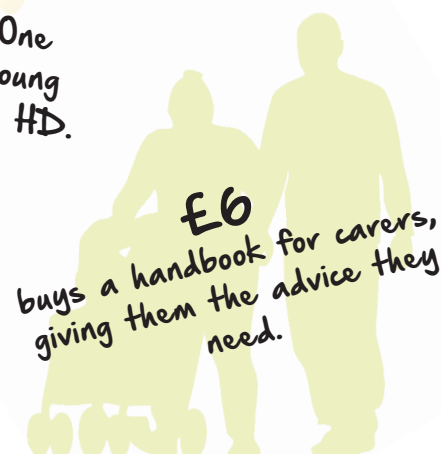
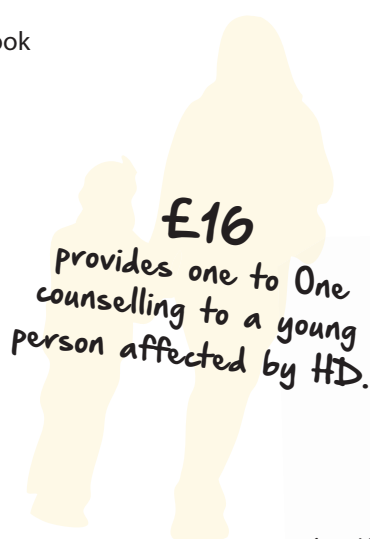
🌻 Welcome.....	Page 3
🌻 What is Huntington's disease & Scottish Huntington's Association?	Page 4
🌻 Case Study.....	Page 5
🌻 A Day in the Life of an HD Specialist.....	Page 6
🌻 Fundraising Stories.....	Page 7
🌻 Our Top Ten Fundraising Tips.....	Page 8
🌻 Frequently Asked Questions.....	Page 9
🌻 Be Loud and Proud - celebrate by promoting you..... event and help raise awareness in the media	Page 10
🌻 A/Z of Fundraising Ideas.....	Page 11
🌻 Donation Payment Form.....	Page 12

Welcome

Thank you for choosing to support Scottish Huntington's Association by organising a fundraising event on our behalf. We are here to support your fundraising effort every step of the way and have put together this information pack with handy hints & tips.

You will be part of an amazing network of fundraisers doing their best to make a difference to the HD community. We wish you every success with your fundraising and look forward to hearing all about it.

So, whether you raise £50, £500 or £1000, every penny and pound will be put to good use and this is the difference your support will make...



What is Huntington's disease?

Huntington's disease (HD) is a devastating neurological condition that causes certain nerve cells in the brain to waste away. Over the course of 15 to 25 years – from the first appearance of symptoms – people with the condition lose the ability to walk, talk, eat and care for themselves. Their ability to think, make decisions and exercise judgement can be affected and they can also suffer emotional and mental health problems.

Around 900 people in Scotland are currently affected by the condition. Most commonly, symptoms appear between the ages of 35 and 44 and, consequently, between 4,000 and 6,000 other individuals are thought to be at high risk of developing HD in the future.

HD is also hereditary. Each child of a person with the condition has a 50% chance of inheriting the same faulty gene.

As yet, there is no cure.



What is Scottish Huntington's Association?

Scottish Huntington's Association (SHA) is the only Scottish charity dedicated to helping people affected by Huntington's disease. Through a network of HD Specialists in nine services around Scotland – Glasgow, Lothian, Lanarkshire, Ayrshire, Highland, Grampian, Tayside, Fife and Angus – as well as our Youth Service, Symptom Management Clinics, and Carers' Support Groups, we provide practical and emotional help for those suffering from HD, and for their carers and families.

SHA is also committed to raising awareness of HD and campaigning for better services for those affected. Independent research commissioned by SHA shows that more than one in five (21%) Scots do not know what the condition actually is. Despite the fact that HD is not a particularly rare condition, it has a relatively low profile compared to other conditions which have a similar prevalence. This is partly because, unlike other conditions, HD is shrouded in fear and stigma. Families are very reluctant to talk about it because of the potential implications for their children, jobs and long-term financial

security. The net result is that even medical professionals can find it difficult to give patients informed advice about the disease, making SHA's services even more vital.

Having worked with people who have HD since the charity was established in 1989, SHA has unrivalled knowledge of the support which is available from local councils, NHS services and other organisations.

£300,000 is needed this year to maintain the level of support we currently provide.



Case Study - Mark and Mandy - Ayrshire



Mandy, 43, was diagnosed with HD in 2005. Although the quality of services provided by SHA prompted the family's move from England in 2007, it wasn't until 2010 that Mark and Mandy came into contact with the Ayrshire HD Specialist Service.

When Mandy began to experience problems with her balance,

significant memory loss and periods of depression, husband Mark decided the time had come to contact the charity to see what support might be available. "The hardest part was persuading Mandy to let the HD Specialist carry out an assessment", says Mark.

"It meant an acceptance of her condition, which she was struggling with. Her mood swings had been bad for some time – at times, she just wasn't herself."

With their two daughters still at home, and a young grandson on the scene, everyday life for Mark and Mandy was becoming difficult. Reluctantly, Mandy agreed to let Eileen Meek, the charity's HD Specialist and Project Manager for Ayrshire, visit the family at home.

"The first thing Eileen did was sort out medication for the mood swings", says Mark. "It made an enormous difference, almost immediately."

Eileen was also able to advise the couple about benefits entitlement. Mark, a part-time National Trust guide, hadn't even considered this. "Eileen helped us through the benefits system minefield. We now have a motability car and Mandy receives Disability Living Allowance."

In addition, Eileen advised the couple about how to better manage their finances, with Mandy eventually agreeing to award her husband Power of Attorney. "This was a huge step for me", admits Mandy. "I'm a bit of a control freak. But the memory loss meant I was struggling to manage our finances – I was forgetting banking passwords, and our accounts were being frozen. It was becoming a real problem, and was causing conflict between us."

Advanced care planning has been a key element of Eileen's work with the couple, involving several sessions with Mark and Mandy over a period of many months. An intensely emotional and difficult process, the end result is a detailed Care Plan, reviewed annually, outlining Mandy's wishes for her future care and treatment as the disease advances. It includes a living will, information on Mandy's values and beliefs, and details of her wishes regarding supported nutrition. Crucially, it lessens anxiety among families about the difficult decisions they'll face ahead.

Perhaps the biggest step for Mandy, though, was to agree to Eileen's suggestion that she attend a nearby hospice for weekly Tai Chi classes, complementary therapies and fatigue management sessions. "I was so reluctant to go anywhere near a hospice", admits Mandy. "But eventually – after months - Eileen persuaded me, and arranged it all, and it's been amazing. It's helped me enormously with concentration and balance, with relaxation, and my energy levels."

For Mark, the support from the Service in talking to the couple's daughters about HD was invaluable. "The day we sat the kids down to talk to them about HD, was the worst day of my life", remembers Mark. "But without the support and advice from Eileen about how best to do this, we'd never have been able to get through it."

"What means most is knowing there's always someone there to support you. The specialist knowledge about medication, benefits and legal matters is hugely important, and the emotional support means so much too."

Mark concludes: "Our life with HD is like a jigsaw, and Eileen is the one who pieces it all together. I feel like I've got Mandy back and our life back. It's been a lifeline for us."

“**The first thing Eileen did was sort out medication for the mood swings, says Mark. It made an enormous difference, almost immediately.**”

A day in the life of an HD Specialist



In 2004 I took up post with the SHA, as a Huntington's Disease (HD) Specialist, based in Fife. Initially, I had no concept as to how varied and demanding my job was going to be. As you can imagine, due to the multi-faceted complexities of this hereditary condition, no two days are the same.

Over the last ten years, and changing with the times, my role has proven to be both rewarding and challenging for various reasons. This has included dealing with unpredictable and crisis situations for clients and their families.

A typical day will, generally, involve carrying out a number of visits to clients in their own home, care facility or hospital to deal with a multitude of different tasks.

Examples of these tasks could be to offer emotional support, give practical advice and guidance, discuss a client's options with regards to genetic testing, liaise with social services and other agencies and co-ordinate a person's care package.

With thorough assessment and follow up visits, all activity is person centred with the aim of empowering people to maintain as much control over their life as possible.

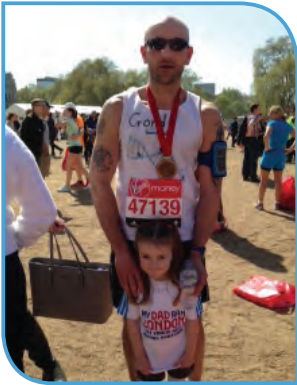
Discussions on symptom management and issues surrounding swallowing, mobility and nutritional difficulties will inevitably lead to referrals to allied professionals. As a study site, a significant part of my remit is to successfully co-ordinate and run a clinic in conjunction with the European HD Network.

This has allowed participants to enrol on to the European database and affords them the opportunity of being considered and recruited for future clinical trials. Delivering regular training sessions and facilitating support groups form an important part of my ever busy work schedule.

Nicola Johns (HD) Specialist, Fife

“ Over the last ten years, and changing with the times, my role has proven to be both rewarding and challenging for various reasons. This has included dealing with unpredictable and crisis situations for clients and their families. ”

What our Fundraisers had to say



Gordon & Skye
London Virgin Marathon

“ An amazing experience for the fourth year running, after all the hard training and raising funds, a great day was had and well worth all the hard work. I'm counting the days to next year. ”



“ It was a great night and for a great cause. ”

Sheena Assiph and Franck Pauly
Cerec dance competition



“ We walked the hot coals for a good cause, it was an amazing night! ”

Mary and Jessie
Dundee Firewalk



“ It was an exciting event, I wanted to do it again. ”

Glasgow Zipslide



Stephen Dunn
Border Cyclista Cycling event.

“ It was pretty horrible conditions over 130 miles including 8500ft of climbing. It was a great experience and lots of money raised for an excellent cause. ”



“ It was fantastic weekend and an honour to raise funds in memory of a friend. ”

Ben Nevis

Top ten fundraising tips...

- 1** Tell your supporters why we so desperately need their help and how their donation will be used. SHA is the only charity in Scotland dedicated to helping people affected by HD. Without our services, 6,000 people would be left without that lifeline. £300,000 is needed this year alone to maintain our services. Refer your supporters to our website (www.hdscotland.org) where they can download our short film, 'Bound Together', which highlights the impact HD has on a family.
- 2** Gift Aid - If your sponsors/donors have paid sufficient tax in any one tax year to cover all their gift aided donations in that tax year, then they should tick the gift aid box on your sponsor form/donation and give their home address and postcode. This will enable us to claim an extra 25p from the Inland Revenue for every £1 raised, at **no extra cost to your sponsor**. We are **not** able to claim Gift Aid if a work address is given. Please ensure you send us your sponsor forms as we need these as proof.
- 3** You can now DONATE to SHA online via our website. Simply visit www.hdscotland.org and click on the 'DONATE' tab in order to give a regular or single donation. It's now easier than ever to support SHA and with your help we can continue to provide vital specialist services to those living with HD in Scotland! Thank You.
- 4** Raise funds online. It is easy to set up your own sponsorship page by registering on www.justgiving.com/hdscotland. Then, email your page to all your friends and family you don't see regularly asking for their support. If you prefer to use paper sponsor forms, ask for the cash at the time of being sponsored rather than waiting till after the event.
- 5** Ask friends and family for help distributing sponsor forms, posters, sourcing raffle prizes, selling tickets. Ask your employer for help. They may sponsor you, match the amount you raise, or help in some other way. Ask local companies for sponsorship, donations or raffle prizes.
- 6** If you are organising an event, keep a keen eye on your budget as increasing costs will eat into any profit you make. Plan your fundraising activity in advance and make sure you leave plenty of time.
- 7** The more people who know about your fundraising, the more money you will raise. Use the local media to publicise your event/fundraising project as widely as possible. Your local newspaper, radio station or 'What's On' guide may be interested in putting in an article and/or photograph. Remember to wear our T-shirt for photographs as this helps raise awareness of SHA and HD.
- 8** Always have information about your activity with you. Whether it is tickets for an event, sponsor forms or posters, you never know who you might bump into who could help you and get involved.
- 9** Always thank your supporters, either in person or by letter. You can also add a personal thank you on your online fundraising page or social media links.
- 10** Finally, let us know what you are planning to do and we will help and advise as much as we can.

Frequently Asked Questions

I want to raise funds for Scottish Huntington's Association but don't know how. Can you give me some ideas?

The A to Z of easy fundraising ideas on P11 in this Information Pack gives lots of examples of the various ways you can support SHA, either by taking part in an existing event or by organising your own. Have a look through our suggestions and give us a call if you would like to chat any of these over.

When you have decided which activity you would like to get involved in, please let us know so that we can keep in touch and support you.

Can you help me advertise my event?

YES... and in lots of different ways!

We can give you posters on the general work of SHA, and posters which you can personalise with the details of your own fundraising activity. We can give you leaflets on our work, a downloadable version of our logo, collection cans, buckets, sponsor forms, gift aid envelopes, and t-shirt(s). You can tell all our 'friends' about your fundraising on our Facebook page (**Scottish Huntington's Association**) and on Twitter.

If you would like to involve your local newspaper and/or radio station, we can give you a template press release which you can personalise with your own fundraising details. Remember you can invite them to send a photographer along on the day (and wear your SHA t-shirt for the picture!)

I am doing a sponsored event and would like to contact the people I don't always see regularly. How can I do this?

Online sponsorship is the ideal way to reach friends, family and colleagues you don't see often. Go to www.justgiving.com/hdscotland, follow the simple instructions to create your own page, and then e-mail it to all your contacts. Their donation is transferred automatically into our bank account, along with their Gift Aid entitlement.

What is Gift Aid?

Gift Aid is a scheme whereby we can claim back the tax you have already paid on your donation. If your sponsors/donors have paid sufficient tax in any one tax year to cover all their gift aided donations in that tax year, then they should tick the gift aid box on your sponsor form/donation and give their home address and postcode. **This will enable us to claim an extra 25p from the Inland Revenue for every £1 raised**, at no extra cost to your sponsor. We are not able to claim Gift Aid if a work address is given. Please ensure you send us your sponsor forms as we need these as proof.

Do I need insurance cover?

Depending on the type of event you are organising, you may need to have public liability insurance. Most commonly, the venue will already have this in place but it is worth checking. Scottish Huntington's Association cannot accept liability for externally organised fundraising activities.

Do I need a licence?

If you intend to hold any form of collection in a public place, you must have a licence from your local council. If your collection is being held in privately owned premises (such as a shopping centre) written permission from the management is needed.

If you are planning to organise a lottery or raffle with tickets being sold in advance of the draw, you will need a licence from your local council. If tickets are only available on the day the draw will take place, no licence is needed.

Can under-16s get involved?

Fundraisers aged under 16 must have authorisation from a parent or guardian and be supervised by a responsible adult. If you are including photographs of under 16s in publicity materials, written permission from their parent or guardian is needed.

I've completed my fundraising event but am finding it difficult to collect the total amount of donations I was pledged. What should I do?

We know it can take time to collect all the donations you were promised, but you don't need to wait till you have received the full amount. Please send us what you have raised so far and just let us know when you expect the remainder.

I've collected all my sponsorship money and donations. What should I do next?

In this pack you should have a 'Donation Payment' form. Please complete this and return to us at the address on the form.

Any cheques should be made payable to Scottish Huntington's Association.

You can also pay money directly into our bank account. Call us on 0141 848 0308 for our bank details. When you have paid the money into the bank, please let us know by email mandy.nichol@hdscotland.org so we can identify your donation. We will also require a copy of the pay-in slip.

Be Loud and Proud

What better way to spread the word than through your local media. Local newspapers and radio stations love local stories and you've just become one. Please remember and obtain permission before printing any family members details in the local press.

Want to be on the radio or in a newspaper?

Media support is free and the publicity will enable you to reach new audiences. Local papers are very supportive of local events and local people getting involved and we'll help you reach them.

What or who has inspired you to take on an event? Do you have a moving story, or a family member you would like to celebrate? Perhaps you have a family member who receives one to one care from an HD Specialist or youth service. Or could you inspire others to get involved and join in.

How to make a great start

Make a list of all the local newspapers or publications in your area.

Find the contact details and call the news desk or editor of the publication or send them a press release or letter about the event and how you're raising money for the SHA. Find out when their publishing their deadline so you can get them all the information they need and photos.

Key messages to include

1. Details of your event
2. Why your supporting Scottish Huntington's Association
3. How much you need to raise
4. What you are planning to do

Press Release Messages

1. Who is doing what.
2. Why are they doing it with a quote
3. What the charity does
4. Contact details and how to show support

Letter to the Editor

1. I am doing XXXX event
2. Why I am doing it
3. What the charity does
4. Contact details and how to show support

Support Letter of Authentication

1. You can get this letter from your fundraising contact
2. It proves who you are and what you are doing, as well as what the charity does.



A to Z of easy fundraising ideas to help you bring in the pennies to make up the pounds...

- ✿ Take on one of our **Adventure challenges**
- ✿ Get stuck in to some **Bag-packing** at your local supermarket, a great way to raise funds
- ✿ Roll up your **sleeves and offer neighbours a Car wash**
- ✿ **Hold a Dress-down day** or crazy socks day at work or at school
- ✿ Log on to **Ebay** to sell your unwanted items and donate some of your proceeds to SHA
- ✿ Use **Facebook** and Twitter to spread the word about your fundraising
- ✿ Get your friends involved in a **Game night**
- ✿ **Host** a coffee morning or fun night in and ask for a contribution from attendees
- ✿ Send off your **Inkjet cartridge** or an old mobile phone for recycling
- ✿ **Jog**, run or walk to raise money at one of many events across the UK
- ✿ Let your hair down at a **Karaoke night**
- ✿ Leave the gift of hope in your **Legacy**
- ✿ In **Memoriam** Celebrate the life of a loved one by making a donation to SHA in their name
- ✿ **Negotiate** with a local business to have a collection can at their till
- ✿ **Offer to collect donations** instead of gifts for a birthday, anniversary or any other celebration
- ✿ Sign up for the **Paris Marathon** or Virgin London Marathon
- ✿ What's your biggest vice? **Quit it** and raise sponsorship
- ✿ Organise a **Raffle** or tombola
- ✿ Plan a **Singing** competition at home or in the local pub
- ✿ Host a **Tea Party** at home or in the local community hall - sign up for SHAre tea for HD
- ✿ **Use your powers of persuasion** to encourage a friend (s) to join in with your fundraising
- ✿ **Volunteer** to do the housework or other tasks for a week/month in return for a donation
- ✿ Why not host a Vintage **Wine tasting event**
- ✿ Take on an **X-treme challenge**: face your fear and take on a skydive to raise sponsorship
- ✿ Tell us **Your own idea** - have you got a suggestion that we haven't thought of?
- ✿ Organise a **Zumba-thon** or any other dance competition.

Donation Payment Form

The form below covers all the possible methods of paying-in your donation including directly into our bank account, our bank details are below. If you pay directly into our account ask for a Bank Receipt and attach it to this form. Please complete this form and send it to our head office so that we can identify who has made the deposit. Alternatively you can send it by email to: mandy.nichol@hdscotland.org thank you.

Name: _____









Address: _____

Fundraising Event: _____

Date of Fundraising Event: _____

Signed: _____

Please tick:

-  I have paid £_____ into the bank on ____ / ____ / ____ (date). Please attach your pay-in slip in order for us to identify your donation. **Bank of Scotland – Sort Code 80-16-53 - Account no – 10056968**
-  I have paid in person to National Office £_____
-  I have enclosed a cheque for £_____ (made payable to Scottish Huntington's Association)
-  I have given £_____ cash to _____ (please give name of SHA representative)
-  I have attached my sponsor forms
-  (Without these, we are not able to claim gift aid)
-  I have raised £_____ online. My page can be viewed at [www._____](http://www._____.)
-  I have attached a CAF voucher to the value of £_____

For Office Use Only:

Date received: ____ / ____ / ____

Cheque £

Cash £

CAF Voucher £

Other £

Total £

Funds recorded on spreadsheet Y/N

Thank you letter sent ____ / ____ / ____

Checked by _____ Date: _____