



# Fundraising guide

Charity no. 1097173

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# Thank you!

Thank you for downloading this guide and beginning your fundraising journey with us. Without you, we wouldn't be able to continue providing information and support for those affected by CJD and prion disease, and those at increased risk. This guide was designed by our previous National Coordinator, Beth Marsh, and this version has simply been updated to take account of a few changes since 2024. Whether you are an experienced fundraiser or just getting started, this guide is here to provide you with what you need to feel confident about fundraising for the CJD Support Network (CJDSN) and includes:

- Information about CJD and prion disease
- Information about the Network
- Highlights of the support we were able to provide in 2023
- Details of the difference you will make with your fundraising
- Inspiration and ideas
- A fundraising 'roadmap' to help guide you on your journey
- Supportive resources

We hope that reading over this guide gives you everything you need to get started, but we are also always here to support you in any way we can. Whether you need help with ideas, publicising an event, promotional materials, merchandise, or something else entirely, we would love to hear from you and do whatever we can to be alongside you every step of the way.

On behalf of the CJDSN Executive Committee...

Thank you,

Catherine  
National Coordinator  
CJD Support Network



# What is CJD?

CJD is one of a group of diseases called prion diseases, it affects 1 – 2 people per million of the population per year. The lifetime risk of CJD is around 1 in 5,000. In 2023, 130 people in the UK died of CJD. Prion diseases are neurodegenerative conditions which are progressive and, tragically, are invariably fatal.

There are three broad types of CJD and prion disease...

Sporadic CJD is the most common form, accounting for around 85% of cases. The cause is unknown, it occurs spontaneously. It mainly affects the over 50s and has a rapid onset. The course of the disease is usually measured in months.

Genetic prion disease is an inherited, or familial, form of the disease, with a generally younger onset and a longer time course than sporadic CJD. Inherited prion diseases account for around 10% of cases.

Acquired CJD refers to rare cases whereby CJD has been acquired by medical procedures, transfusions, or contaminated food.

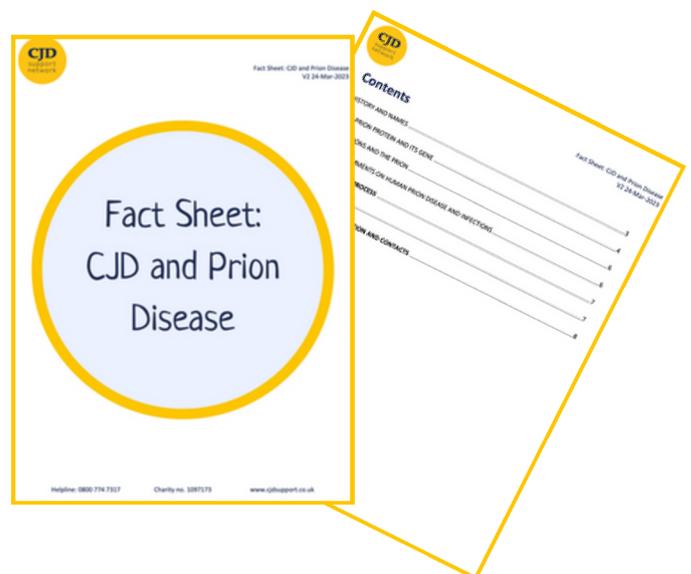
Symptoms of CJD and prion disease...

The precise symptoms and clinical time course of CJD vary according to the type of disease, and from person to person. Symptoms reflect brain dysfunction and certain features are common in all types: memory problems, confusion, clumsiness, unsteadiness, and jerky movements with progressive disability leading to loss of awareness, loss of mobility, loss of speech, and the need for full nursing care.

For more information....

More detailed information on the the disease, symptoms, the diagnostic process and other relevant topics can be found in Fact Sheets on our website, which are regularly updated and provide accurate and unbiased information written by national experts in CJD.

In the additional resources section of this guide, you will also find a leaflet which gives brief information and can be used for awareness and fundraising.



# What is CJD? – Sally’s story

The following extract is from an [article on our website](#) by Sally, whose dad Peter passed away in 2015 with Sporadic CJD...

My Dad was born in 1940 to a hard-working, impoverished family in Manchester. As a young man, he worked hard, becoming a nuclear construction engineer and volunteering overseas – first in Kenya teaching English and later in Ethiopia as a civil engineer. Eventually, my dad left the nuclear industry to retrain as an actor at the Bristol Old Vic.



When he was 70, he went on a six-month solo trip to India which he loved – whilst there he started writing a book called his ‘Adventure before Dementia’.

In October 2014 dad was 74 and still working on various projects such as the odd acting job and directing at his local theatre group. He began to suffer from mobility issues. Walking was becoming more difficult and he began needing the support of a wall behind him if standing. He developed an extreme tiredness, anxiety, and trouble sleeping. Dad was losing weight and unable to remember family and friends, however, the GP continued to diagnose his symptoms as those of a stroke.

In February 2015, my dad was admitted to the hospital after a neurologist who had seen him previously was shocked at the progression of his symptoms. By this point, he was unable to speak. Despite this, we could see that he was trying to smile, to communicate to us that everything was fine – I’m so glad that he knew we were there. Dad had a lumbar puncture and we received the diagnosis of CJD two days before he died on 21st February 2015. I am still coming to terms with what happened but am grateful for the opportunity from the CJD Support Network to tell my story.

To read more from the people at the heart of our network, those who have been personally impacted by CJD and prion disease, head to the ‘[Real Stories](#)’ section of our website where you will find a number of articles including...



[Roger’s account](#) of his wife Sharon’s illness with CJD.



[Dave’s account](#) of living at increased risk of iatrogenic CJD.

# About us

The CJD Support Network was set up in 1995 by relatives of people who have died with CJD and prion disease, and is the only UK charity dedicated to the disease. Our mission is to help ensure that appropriate practical and emotional support is available for all forms of prion disease in the UK, and those at increased risk. We also aim to support and advance medical and scientific education and research.



## CJD Support Network



We provide information on CJD and related topics, via our website, fact sheets and videos. We can be contacted by email or phone with specific questions. We are supported by national experts to provide accurate and up to date information.



We offer listening support via email and phone. We offer caring grants for those in financial need and research grants for work on any aspect of CJD - particularly research related to care and support.



We link people with similar experiences via our online community, our in person annual meeting, other occasional in person meetings, and regular online meetings for those with a personal connection to all forms of the disease.



# 2024 Highlights

8,929

UK visitors to our  
website  
2023 - 4,100

400+

People supported 1:1  
via phone and email

100

New families joined  
our online peer  
support community

50+

People attended  
our 12 online peer  
support meetings

72

People came  
together at our two  
in person events

10

Families supported  
with one of our  
Caring Grants

# The difference fundraising makes...

**£10**

Pays for one person to be supported by telephone

*"Being able to phone and ask questions when nobody is answering your questions, is a lifeline."*

Jean - husband Julian passed away with CJD

*"With a disease as rare as this it was really good to find people who knew more about it, rather than reading random things on the internet"*

Sudheer - Father Ramesh passed away with CJD

**£50**

Keeps our website and fact sheets updated for 1 month

**£100**

Pays for two family members to attend our family support weekend

*"It's been so helpful to learn a lot more in detail about this awful disease, speak to the professors with any questions we have, and meet other families who have unfortunately been through this too but really understand."*

Abigail - Mum Ruth passed away with CJD

£150

Pays for one of our online support groups for the whole year

*"Connection with other people affected by CJD - sharing our experiences, pain and mutual support within the safe facilitated framework is so beneficial. "*

Andrew - Husband James passed away with iCJD

*" Thank you from the bottom of my heart for this grant.. it's truly appreciated and relieves a lot of fiscal pressure from me, while being off work to look after my mother."*

Marc - Mum Dorothy passed away with CJD

£500

Supports a family with one of our caring grants

£25k

The research grants we were able to offer in 2023 thanks to our fantastic fundraisers and donors

... and what it means.

# Fundraising inspiration

Need an idea to get you started? Here you'll find examples taken from just a few of our fabulous fundraisers. See if any of these ideas take your fancy, or perhaps give you inspiration for coming up with something else...



Liza held a bake sale at work



Dave walked the Dales Way



Kirsty held back to back exercise classes



Kelly made and sold remembrance stones



Vicky and Grace took on Tough Mudder



Sam did a birthday fundraiser



Paul ran a Marathon



Emelia did a bungee jump



Matthew cycled from London to Brighton

# Fundraising inspiration: Libby's story

Libby's mum Jane had sporadic CJD and passed away in March 2023. Libby says:

"Mum loved making personal pieces of jewellery. She enjoyed designing and giving these gifts and got true enjoyment from the time spent with her thoughts whilst creating the jewellery, thinking about all the times spent with the person and reflecting on their journey and relationship. It was as if Mum channelled the person she was creating the piece for.



Mum was a self-confessed perfectionist, and would often attempt unsuccessfully to make a bracelet with a 'random' selection of stones. Instead, mum decided to include one unique element to every bracelet she made, whether that was a stone that didn't match the bracelet's aesthetics, was made of a different material or was a different shape or size. "

As a beautiful tribute to Jane, Libby and her daughter Jessica started making bracelets with one random stone or bead which the CJD Support Network sell under the name 'One Unique Stone - showing that your journey is your own'. The bracelets act as a reminder that we stand together, never alone, in our experience with CJD. Each bracelet's unique stone also shows that, whilst we stand together, every individual's journey with CJD is as unique as they are. With bracelets sold at £5 each, the CJD Support Network has raised over £250 from sales of 'One Unique Stone', and counting!



## Calling all crafty creatives...

If you are inspired by Libby's story and can draw, paint, knit, crochet, make cards or enjoy anything else crafty and creative, and would be happy to make things for us to sell, please get in touch. We'd love to chat with you about the possibility of stocking your items, listing them on the 'Shop' page of our website, or selling them at our in person events.

# Featured fundraisers:

## John Cook's Friends and Family



John Cook passed away with sporadic CJD in February 2022, with his daughter Rachel and his beloved wife Karen by his side. John was a kind-hearted, loving and straight-talking man who loved spending time with his family, friends and his dog Marley.



Inspired by John's love for walking, Karen, Rachel, friends and family (including Marley, of course) began their fundraising journey with a walk around the beautiful Erddig estate. The group raise over £1,000.

### May 2022

John's grandchildren Lily and Tyler make beaded jewellery (with help from mum, Rachel), selling it online and at school. Lily organises a school non-uniform day to raise money in memory of beloved Gramps, with over £550 raised.

### June 2022

Rachel's husband Paul runs 10 miles a day for 10 days in memory of John. Son Tyler joined Paul for the last mile of this amazing challenge, with over £130 raised.

### August 2022

Rachel held a raffle to win a TV donated by her employer, tickets were £3 each and Rachel raised over £500 in total.



## September 2022

Family friend Pete pushed the Great North Run in his everyday wheelchair completing the course in a fantastic 2h 2min, raising £878 in memory of John.

## November 2022

John's Nephew, Warren held weekly quiz nights at his restaurant Lateral by Wylde in West Kirby, selling pens and wearing CJDSN t-shirts during the quizzes.



Overall, in 2022, John Cook's family and friends raised over £3,000 for the CJD Support Network, and they haven't stopped there...



## August 2023

John's wife Karen held a fantastic gin and prosecco picnic, including a raffle and with lots of happy memories of John shared, raising a further £425.

### Making all the difference...

The CJD Support Network would like to say a huge thank you to John Cook's family and friends for the difference they have made...

Money raised in 2022 was enough to pay for the room hire, tea, coffee, and lunch for all attendees at our annual family day.

Money raised at Karen's picnic covers Sporadic and Former Carers support groups for 2023, plus phone support for 12 people

It is because of John's loved ones, and all of our incredible fundraisers, that we are able to continue our work.

# Thank you!

# Fundraising road-map

Everyone's fundraising journey, much like everyone's CJD journey, is unique. We've laid out a rough fundraising road map to help you along, but do feel free to try out different routes and don't hesitate to get in touch with us if you ever feel a little lost! The first step is to decide to begin your fundraising journey, the good news is that if you're reading this guide you're already on your way!!

## WHAT?

Consider what kind of fundraising activity you want to do. This may involve something you're good at (baking, running, writing, drawing, fashion), or if you are fundraising in memory of someone, it may involve something close to their heart.

Think about what kind of thing is going to get people donating, as well as what you will enjoy or would like to challenge yourself with. Fundraising should be fun (the clue is in the name!) so choose something that you will like or find exciting.

Fundraising could included an incredible range of activities including clothes swaps with charged entry and donations, bake sales, cricket matches, quizzes, gold tournaments, crafting for our merchandise, giving talks, sponsored silences or reads for little ones, and of course:

## CHALLENGE EVENTS

As a small charity, we work with an organisation called '[Run for Charity](#)' to help us source places on challenge events all over the UK. These truly can be something for the whole family including walks, inflatable obstacle courses

Event	Location	Costs and Notes
Inflatable Event 2/5k/5k/10k/15k	All over the UK	Jump, slide, bounce your way to the finish line. Minimum age is 5. c. £30
Virtual Everest Climb	Where you are	Climb an elevation of 8,848m over 12 weeks, upload your evidence, receive a medal. Minimum age is 5. c.£15
Run Alton Towers Kids Race 5K/10K/Half Marathon	Alton Towers	Run entry includes entry to the park and rides, with spectator tickets available. C. £30 Kids Race - any age, 5K - 11, 10K - 15, HM - 17
160ft Bungee Jump over Water	All over the UK	Take in historic harbour from many many angles. Minimum age 14. c. £85 Bristol / c. £110 Whitby



The only big events we cannot access through Run for Charity are the London Marathon and the Great North Run, however we can explore options for these each year. Get in touch to discuss aiming for these. As we are a very small charity, entering in the ballot is, for now, the best way to access London entry.

Entry fees can be a barrier to people taking part. If this might apply to you, please feel able to contact us to see if we can support you in some way.

### WHEN?

Make sure you give yourself enough time to plan and promote your fundraising activity properly. The amount of time you need will vary depending on the fundraising you are doing, but consider... how long will I need to prepare for this?

If you are taking part in a challenge event, such as a marathon, plan to make sure you have time to train for it. If it's an event you are organising yourself, consider what time of year would be best - do you need to think about weather, and when people are most likely to be available to attend or support?

- 28 February - Rare Disease Day
- May - National Walking Month
- First week of June - Volunteer Week
- 12 November - CJD International Awareness Day
- And of course a day that has meaning to you, or the person you are fundraising in memory of.



### WHO?

Fundraising can be even more satisfying if done in a team or with the support of your community. For example, is there anyone who could join you on your fundraising adventure? Maybe someone who has skills that complement yours, or someone who will keep you motivated. Getting others involved can help you reach different people and raise more money.

Does your employer offer 'matched funding' for their employees fundraising for charity? Is there a chance to nominate CJD Support Network as a workplace charity, or for supermarket 'token' boxes?

Are there other people near you who may also have been affected by CJD and might like to form a team with you?



## PROMOTION

Once you have decided what you want to do, it's time to promote your fundraising activity. This may be difficult to do - no one likes asking people for money - but promotion is key to making sure your fundraising is successful. Don't be shy! If you're struggling, ask others to help you and promote what you are doing, too. Below are some helpful tips for promotion:

Set a target for the amount you want to raise. This will depend on the type of activity you are undertaking - try to go for an amount that is ambitious but achievable.

Prepare some text to present your fundraiser. The more personal the better, but only include what you're happy to share. You might:

- Give info about CJD and the CJD Support Network
- Share why you are supporting the charity
- Say what people's donations will be used for
- Explain what you will be doing and when

Set up a fundraising page where people can donate. Setting up a page via JustGiving is straightforward and means that people's donations will go straight to us, follow this link and click 'Fundraise for us':  
[www.justgiving.com/cjdsupport](http://www.justgiving.com/cjdsupport)

Share your 'call to action', and fundraising page. If fundraising in honour of a particular person, consider asking people close to them to be involved:

- Use leaflets - make your own or use the additional resources in this guide!
- Free QR code generators are great ways to link to your justgiving page on leaflets or posters.
- Send emails, texts, or WhatsApp to family, friends and colleagues
- Post on social media - don't forget to tag us:
  - X: @supportCJD
  - FaceBook: @CJDSupportNetworkUK
- Reach out to people who may not give online, with the option to donate in cash, you can then donate to your fundraising page on their behalf

Remind people! After sending your initial call to action, make sure to give people regular updates on how your fundraiser is progressing: how much you have raised so far, how the preparations are going, etc. A lot of people will need to see the information a few times before actually getting involved, and those who have already donated will be happy to see you working hard!

Now, enjoy completing your fundraising activity!



# Fundraising road-map

## NEXT STEPS...

Once you have completed your fundraising activity, as well as giving yourself a huge pat on the back, thank the people who have supported you. You could send out a final update, letting everyone know how much you have raised and what it will be used for.

In your final update, you may wish to encourage people to visit our general JustGiving page where they can click 'Donate' to make a further one off donation, or even set up a monthly donation (every little helps!) and become a regular donor:

[www.justgiving.com/cjdsupport](http://www.justgiving.com/cjdsupport)

Looking to the future, why not think about how you might build on your fundraiser? Perhaps you'd like to hold another event, reach a particular fundraising target or make it a tradition and do something annually for the CJD Support Network.

Please also email us to share pictures of your fundraising, as well as all your tips and tricks to help others to fundraise:

**What has worked for you?  
What didn't?  
What did you enjoy the most and what has been difficult?**

**WELL  
DONE!**

## Raising Awareness



Raising awareness is something that can involve fundraising, but does not always need to. In 2025 we supported a Lead Nurse for CJD within surgical theatres to hold an awareness session linked to International CJD Awareness Day. We were able to discuss the main aims of their session, and help produce materials that suited their context.

If you have an awareness raising idea feel free to contact us to see if we can support you. Examples of previous posters are on the final pages of this guide.

# Further support



At all stages, make sure you look after yourself. Be safe and pace yourself. Don't forget we're here!

By reading this guide, you have already begun your fundraising journey. If you're ever feeling a little lost along the way, please don't hesitate to get in touch:

**[support@cjdsupport.co.uk](mailto:support@cjdsupport.co.uk)**

**0800 774 7317**

**08:30-15:30 Tuesday**

**11:00-18:00 Wednesday and Thursdays**

# CJD

support  
network



## What is CJD?

CJD is one of a group of rare, rapidly progressing, and invariably fatal diseases called prion diseases, it affects 1 – 2 people per million of the population per year. Lifetime risk is ~1 in 5,000.

There are different forms of the disease, but certain symptoms are common in all types: memory problems, confusion, unsteadiness, and jerky movements with progressive disability leading to loss of awareness, mobility, speech, and the need for full nursing care.

## What is the CJD Support Network?

CJD is a devastating disease and, as it is so rare, can leave individuals and families feeling extremely isolated. The Network was set up in 1995 by relatives of people who have died with CJD, and is the only UK charity dedicated to the disease. Our mission is to help ensure that appropriate practical and emotional support is available for all strains of CJD in the UK. We also aim to support medical and scientific education and research.

## What does the CJD Support Network do?

The Network is completely funded by donations, which enable us to provide practical and emotional support via our national helpline and support email service; support those in financial need through our caring grants; link those with similar experiences via our online community and in-person events; provide research grants to further knowledge about the disease, and provide information to professionals who wish to learn more.

## What does it mean?

"We knew there were awful symptoms coming...at last we had a body of people we could go to. They've been marvellous to us, and still are."

CJD Support Network Member

Registered charity  
no. 1097173

[www.cjdsupport.co.uk](http://www.cjdsupport.co.uk)  
0800 774 7317

**CJD**  
support  
network

Charity no. 1097173

# International CJD Awareness Day 12 November

- Prion diseases can be sporadic, inherited, and in specific circumstances have been acquired.
- Sporadic CJD is the most common prion disease, it progresses rapidly and seems to happen at random, usually between ages 45-75.
- Prion diseases have no treatment and at present are always fatal.
- The CJDSN exists for the benefit of all those who have a connection to CJD and prion diseases.

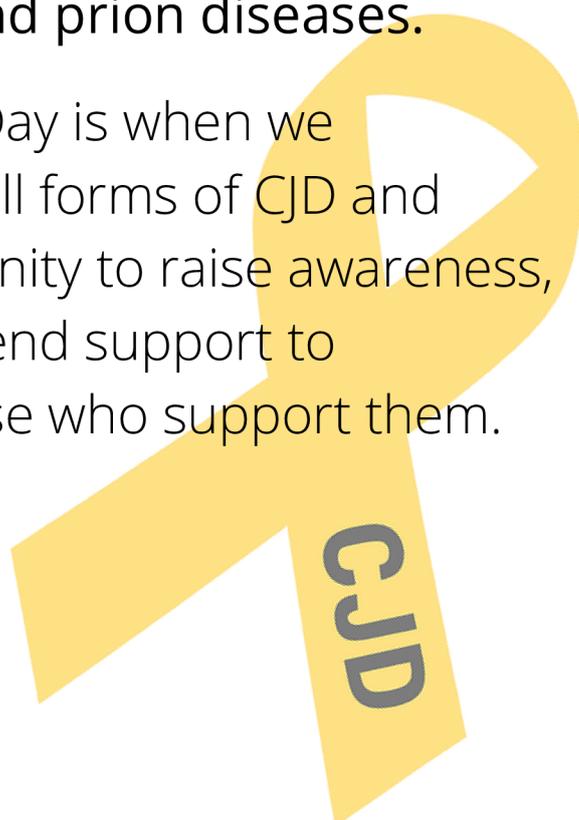
International CJD Awareness Day is when we remember those affected by all forms of CJD and Prion Disease. It is an opportunity to raise awareness, destigmatise prion diseases, lend support to everyone affected, and to those who support them.



[cjdsupport.co.uk](http://cjdsupport.co.uk)



Donate via JustGiving



**CJD**  
support  
network

Charity no. 1097173

# International CJD Awareness Day 12 November



At [name] Hospitals NHS Trust, Surgery Division, you can approach Deputy Matron [Name] or Senior Staff Nurse [Name] to find out more information about how CJD, and Iatrogenic CJD in particular, affects Theatre practise.

**CJD Support  
Network UK  
Website**



**Public  
Health  
England on  
CJD**



**Real Stories  
from the CJD  
Community**



**Fact  
Sheets by  
CJDSN UK**



**'A Roller-  
coaster of  
Uncertainty'  
Student Voice  
essay by  
Amber Naeem**



**CJDSN UK  
JustGiving  
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