



Huntington's
Disease
Association



Travelling and holidays when you have Huntington's disease symptoms



Travelling or going on holiday can present challenges when you have Huntington's disease symptoms. It can really help to plan ahead to ensure that things go as smoothly as possible. Here are some ideas that might help make things a little bit easier.

Preparing for travel

- Passport photos - If you have problems meeting the requirements for a passport photo due to involuntary movement, or another reason, then the advice is to send as good a photo as you can and explain the reason for not meeting the requirement when you submit the photo. For more information about this please visit: www.gov.uk/passport-services-disabled
- I have HD card - It can be really helpful to order an 'I have HD' card from the Huntington's Disease Association. It gives a short, simple explanation that you have a medical condition that can affect the way you move, think and speak. The card can be especially useful when travelling to places that use biometric checks, as involuntary movements can make it harder to stay still for things like fingerprinting or facial scans. Showing the card can help staff understand more quickly and can prevent misunderstandings – for example, someone assuming you're drunk or not cooperating.
- Sunflower lanyard - It may also help to obtain a Sunflower Lanyard. The Sunflower Lanyard scheme was set up to indicate that the person wearing it has a hidden disability and may need some extra help. Lanyards are available for free at a lot of large supermarkets in the UK. It is also possible to buy a Sunflower Lanyard with the Huntington's Disease Association logo on it from the Huntington's Disease Association online shop www.hda.org.uk/shop/merchandise
- Accessible places to visit in the UK - If planning trips within the UK there are websites that provide information on the accessibility of places to visit, stay and eat. These include AccessAble: www.accessable.co.uk/ and Euan's Guide www.euansguide.com/.





Preparing for travel continued:

- Travel insurance- Think about travel insurance. If you have Huntington's disease symptoms you need to take particular care when shopping around for travel insurance. If you don't tell your insurers about having Huntington's when asked if you have any 'pre-existing condition', your insurance could be invalid. You should also check if the policy covers any equipment you need to take with you. The British Insurance Brokers Association (BIBA) website can help you identify an insurance broker. They also have a helpline. Tel: 0370 950 1790 www.biba.org.uk.
- UK Global Health Insurance Card - Make sure you have a UK Global Health Insurance Card. It is free to get a card and it lasts for 5 years. This is different to travel insurance. The NHS website explains: 'The UK Global Health Insurance Card (GHIC) lets you get necessary state healthcare in the European Economic Area (EEA), and some other countries, on the same basis as a resident of that country. This may be free or it may require a payment equivalent to that which a local resident would pay' www.nhs.uk/using-the-nhs/healthcare-abroad/apply-for-a-free-uk-global-health-insurance-card-ghic/
- Medication - If you are taking medication make sure that you have enough to cover while you are away and some extra in case you are unexpectedly delayed and are away longer than you anticipate; carry your medication in your hand luggage so it is accessible; take a copy of your prescription list. For more tips around travelling and medication please read this blog: www.hda.org.uk/travelling-with-medication/. For more information about travelling with medicines, mobility equipment and other medical supplies please visit: www.caa.co.uk/passengers-and-public/passenger-guidance/health-guidance/health-information-for-passengers/travelling-with-medicines-mobility-and-medical-equipment/
- Finding toilets when travelling - If you are travelling in the UK and it is important to be able to find a toilet quickly then plan toilet stops. The UK Toilet Map lists public toilets near you www.toiletmap.org.uk/. You can find the nearest accessible toilet by searching via the Changing Places website: www.changing-places.org/. A RADAR key will enable you to access locked accessible toilets in the UK. You can purchase RADAR keys online.



Help when travelling by plane

If you have a disability and are travelling by air, it is often possible to arrange for assistance at the airport and when on the plane. This could be things like arranging for a wheelchair to get around the airport, or support to get onto the plane and store your luggage. Some airports have quiet lounges where there might be less distractions and noise. For more information about how to arrange assistance in advance please visit the Civil Aviation Authority website: www.caa.co.uk/passengers-and-public/special-assistance/accessing-special-assistance/. If you use a wheelchair, some holiday companies can arrange accessible transfers from the airport to your accommodation, using vehicles that are adapted for wheelchairs instead of the usual coach transfers. It's worth getting in touch with your holiday company to see if this is something they can offer.

Help when travelling by train

If you are travelling by train in the UK then Passenger Assist enables you to request help in advance. This could be help to navigate round the station; to help you get on board your train or to meet your train to help you off; or help to carry your luggage. For more information visit National Rail: <https://www.nationalrail.co.uk/help-and-assistance/passenger-assist/>

Help when travelling by sea

For information about support when you have a disability and are travelling by sea, please visit: <https://www.gov.uk/transport-disabled/ships>

Help when travelling by coach

If you are travelling by National Express and have problems with mobility or might need extra assistance you can get in touch with their contact centre to discuss what support you might need:

www.nationalexpress.com/en/help/contact





If you are driving

If you have a Blue Badge to permit you to park closer to where you need to be, you can use it in some European countries. For more information visit: www.gov.uk/government/publications/blue-badge-using-it-in-the-eu/using-a-blue-badge-in-the-european-union

Booking a holiday

There are several websites where you can search for holidays suited to your needs if you have particular accessibility requirements. For example, if you need equipment to help you use the bathroom or get in and out of bed. Some of these websites are listed below. The Huntington's Disease Association is not in a position to recommend any of these companies so this list is provided for information only.

Disabled holidays www.disabledholidays.com

Enable holidays www.enableholidays.com

Limitless Travel – group holidays for people with disabilities
www.limitlesstravel.org/disabled-holidays

It can be really helpful to get in touch with your accommodation before you travel, just to chat through any adjustments they might be able to offer.

Funding for a holiday

If paying for a holiday is a challenge then it could be worth exploring whether you may be eligible for a grant towards the cost of this. There are several charities who award grants to enable people with disabilities to have a short break, for example the Victoria Convalescent Trust victoriaconvalescenttrust.org.uk. You can contact the Huntington's Disease Association to see if they know of any funding you may be able to apply for: 0151 3315444 / info@hda.org.uk. The charity, Scope, has more information about saving money on days out and travel for people who have a disability and carers: www.scope.org.uk/advice-and-support/free-discount-event-pa





Saving money on travel

To get up to a third off rail travel you can apply for disabled person's railcard: www.disabledpersons-railcard.co.uk

For reduced cost coach travel National Express offer a discount card to people who have a disability:
www.nationalexpress.com/en/offers/coachcards/disabled

On coaches operated by FlixBus it is possible to get a free ticket for a companion, if the person with Huntington's requires someone to accompany them: help.flixbus.com/s/article/PSSP-What-are-the-costs-for-my-travelling-companion-or-my-companion-dog?language=en_GB

Many people with Huntington's disease are entitled to a disabled person's bus pass that allows you to use local bus routes at a discounted price. To apply for a disabled person's bus pass please contact your local authority. For more information see: www.gov.uk/apply-for-disabled-bus-pass



Helpful Tips for holidays and travel with Huntington's

- Share plans at the right time - Some people with Huntington's feel more comfortable when they know the schedule well in advance. Having a clear idea of what will happen and when can reduce uncertainty and help lower anxiety. But remember that timing is personal. For others, knowing travel plans too far ahead can actually increase anxiety so for them it may be better to share the details much closer to the date so there's less time to worry.
- Giving time, space and reassurance when planning - People with Huntington's may decline to participate in a holiday plan because they are struggling to process what it will require them to do. Break it down into small sections. Reassurance is really important to try to reduce worry. It may be an idea to drop the conversation and pick it up later once the person has had time to get used to the idea.
- Keep routines where you can - Familiar mealtimes, bedtime habits, or morning routines when away from home can make new environments feel more predictable and reassuring.
- Use clear, simple communication. Short, straightforward explanations and one step at a time can make things easier to process, especially in busy or unfamiliar settings.
- Offer a simple printed itinerary - A clear, easy-to-read schedule that the person can keep with them can provide reassurance and something to refer back to throughout the trip.
- Show pictures of where you're going - Photos of the airport, hotel, or other key places you will be visiting can help reduce the sense of the unknown and make the journey feel more familiar.
- Plan for extra rest - New environments can be particularly challenging when you have Huntington's. The extra thinking and processing involved can be tiring, so build rest breaks into your day.
- Have a calm "waiting plan" - Travel often involves queues or delays. Waiting can be difficult for people with Huntington's. Bringing something soothing – music, a favourite item, or a quiet activity – can help pass the time more comfortably.
- Identify quiet spaces - Busy places like airports or stations can be overstimulating. If possible, find quieter areas to wait in.
- Allow extra time for everything - Rushing increases stress for everyone, and especially for someone who needs more time to process information or move around.



Helpful Tips for holidays and travel with Huntington's continued

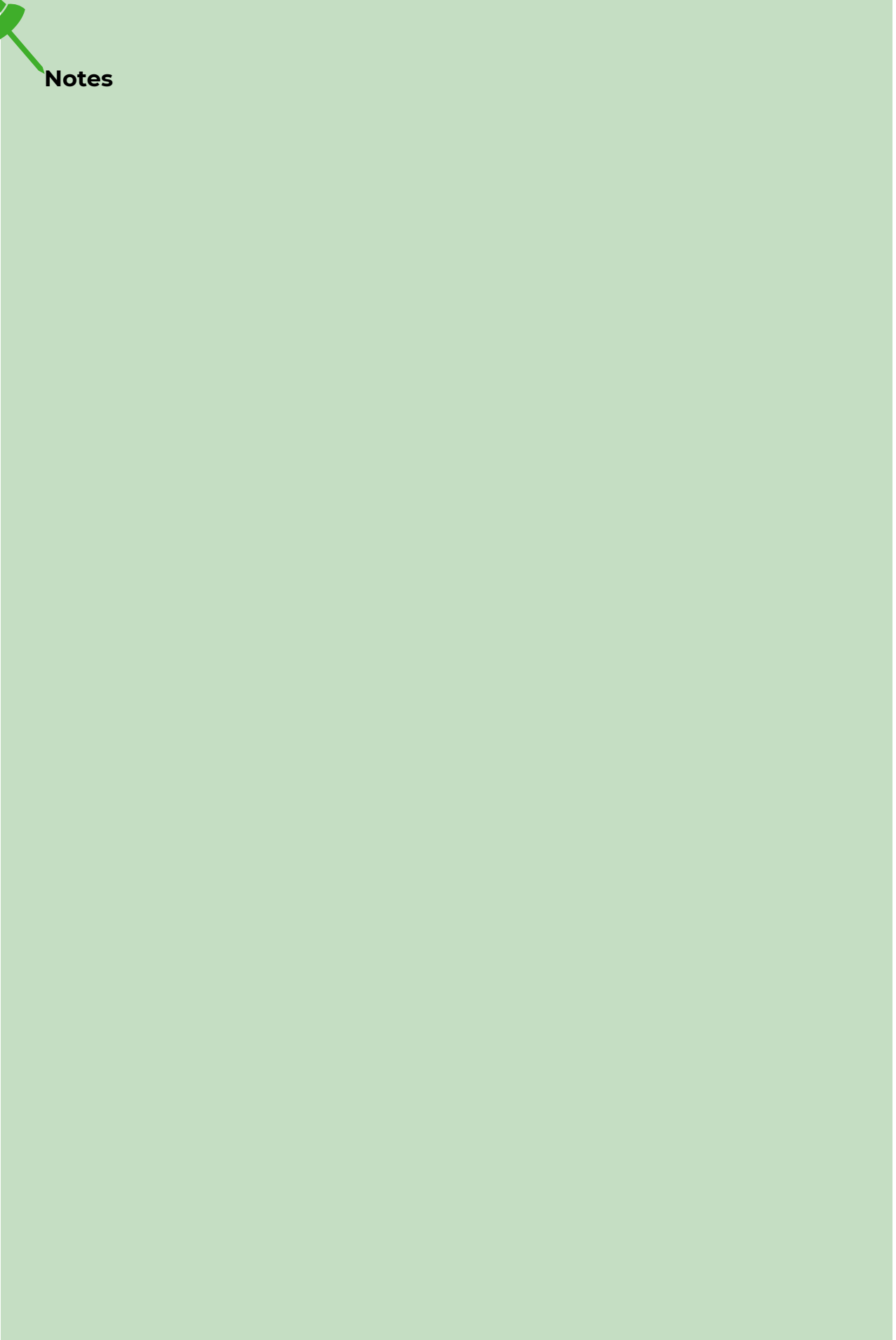
- Bring snacks and drinks - Feeling hungry or thirsty can heighten anxiety. Having suitable snacks and drinks on hand helps keep energy and comfort levels up, both when travelling and when you are at your destination. There may be restrictions on what foods you can carry when travelling to different countries so it is a good idea to check.
- Check in regularly - Gently asking how the person with Huntington's is feeling or whether they need a break can help you spot early signs of fatigue or stress.



Notes

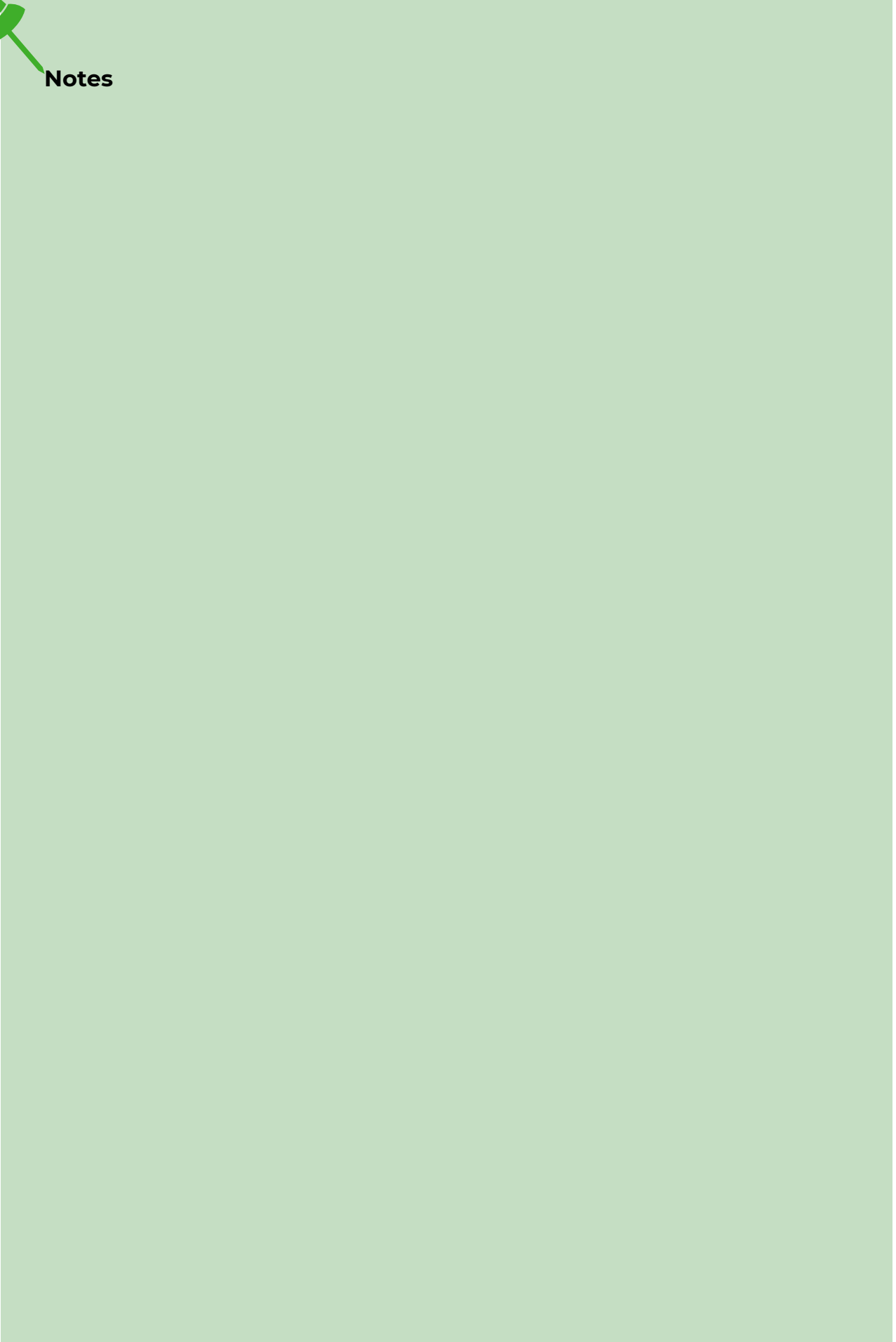


Notes





Notes



Get in touch

For advice and support or
to speak to a Specialist
Huntington's Disease
Adviser

Email: **info@hda.org.uk**

Phone: **0151 331 5444**

www.hda.org.uk

 Huntington's Disease Association

 @hdauk

 @hdauk

 @hda_uk

 Huntington's Disease Association

Huntington's Disease Association

Liverpool Science Park IC1,
131 Mount Pleasant,
Liverpool, L3 5TF

Registered charity no. 296453

A company limited by guarantee.
Registered in England no. 2021975

Inspired by our community