

Ageing carers of brain injury survivors



This publication is part of Headway's *Family and relationships issues* series. To browse through our publications on a range of issues relating to brain injury and download these free-of-charge, visit www.headway.org.uk/information-library.

Introduction

Carers of brain injury survivors often have a number of practical things to regularly think about, such as managing finances, making appointments, preparing meals and providing transport, to name but a few of the jobs that typically make up a carer's day.

Many carers are conscious of how key their role is in the survivor's life and can be troubled by the thought of who will care for the survivor when they are no longer able to themselves, or when they are gone.

This is something that none of us like to think about, but is unavoidable for carers who have been the primary, and often only, form of support available to a survivor. However, it can be difficult to know where to start with making suitable arrangements.

This publication has been written to offer some suggestions of ways in which you can plan for the future.

Practical suggestions

Talk to your loved one

When thinking about future arrangements, start off by speaking with the brain injury survivor and asking them if they have any questions. They might have concerns or fears of their own, and it is important to be able to openly discuss these and provide reassurance where possible.

Have discussions with the survivor when you are both feeling calm and relaxed and are likely to not be interrupted. Consider writing things down such as questions raised or ideas discussed, if this will help the survivor to process information or remember it later. Have brief, regular discussions rather than one single, long discussion, as this might be more beneficial if the survivor has difficulties with concentration or fatigue.

Helpline: 0808 800 2244
Email: helpline@headway.org.uk
Web: www.headway.org.uk



Even if the survivor has problems with processing information, involve them in these discussions as much as possible.

Identify the types of care you are providing

Consider making a list of the types of care that you are providing that someone will need to take over. For example, are you helping the brain injury survivor with activities of daily living such as washing and dressing? Do you have to prepare meals for them? Are you responsible for arranging their transport or accompanying them on outings or to appointments? Are you responsible for managing their finances? Do you provide them with emotional support? Identifying the types of care you are providing can help with making future arrangements, as you can consider who would be best placed to take over each of these different aspects of care.

Talk to family and friends

Start having discussions with family and close friends about your thoughts around arranging future care for the brain injury survivor. This can help you to feel emotionally supported with what can be a difficult and stressful thing to think about, and your family and friends may have suggestions or advice of their own they can share.

If appropriate, you could consider asking family and close friends if there are aspects of care that they would be able to take over, such as offering to do the survivor's shopping, taking them to appointments or having regular phone calls to 'check in' with them. It might be possible to set up a schedule whereby people take turns with these aspects of care.

Even though circumstances may change in future, it can still be helpful to have these discussions in advance so that people in yours and the survivor's life are aware of the support that might be required in future.

Consider who might take over deputyship

If you are acting as a deputy for the brain injury survivor, start thinking about who

Helpline: 0808 800 2244
Email: helpline@headway.org.uk
Web: www.headway.org.uk

could act as their deputy in future. This is a big responsibility, and ultimately it will be the Court of Protection who decides on the replacement, but you can start to consider who might be good for this and approach them to find out how they feel about the possibility of making an application to become the survivor's deputy in future.

The person you approach for this should be made to understand what deputyship entails and how they would apply for this. They also need to be over 18 and should know the survivor well enough to be able to make decisions in their best interests. You can share information with them from the UK government's website at www.gov.uk/become-deputy.

More information about deputyship is also available in our publication [*Mental capacity: supporting decision making after brain injury*](#).

Write a will

Make sure that you have a will in place. Writing a will ensures that your wishes regarding passing assets (money, property) are guaranteed to be fulfilled and that your loved one is provided for in the future.

Legal advice should always be sought when writing a will, particularly when leaving money to someone who is dependent. For more information on writing a will and how you can leave a gift in your will to Headway, visit www.headway.org.uk/donate/a-gift-in-your-will.

Research local services

Find out about what support your local social services can offer and the process for making arrangements. For example, your local social services team might be able to advise on housing arrangements that may need to be considered, such as alternative accommodation or provisions for support within the existing home. If you are struggling to continue providing care yourself, they might be able to arrange for the survivor to have a needs assessment.

Helpline: 0808 800 2244
Email: helpline@headway.org.uk
Web: www.headway.org.uk



Speak to other carers

Other carers of brain injury survivors may have similar thoughts or concerns about future care arrangements and may be able to offer helpful advice. You can find out if your local Headway group or branch has a carers group you can attend to meet other brain injury survivor carers, or make contact with carers through carer support organisations. You can also consider using the Carers UK forum at www.forum.carersuk.org.

Visit care provider

If it will not be possible for the brain injury survivor to live independently in the future, and it is likely that they will need to move into a residential unit or supported living, consider identifying and visiting care providers in advance. This can give you peace of mind that you are selecting the right place or service for your loved one, as well as giving the survivor an opportunity to visit the accommodation in advance and share their opinions and preferences.

Write a future care plan

Write down any plans and arrangements that you would like to be considered in future in a single document called a 'future care plan'. Share information in this with the brain injury survivor and others who will need to be familiar with it, such as family and close friends. Keep this document in a safe place and consider reviewing it periodically to check that your suggested arrangements are still suitable and relevant.

A carer's view...

"When our son fell while on a mountain in Scotland in 1994, my wife and I were catapulted into a world previously unknown to us.

"In our mid-fifties, we were looking forward to making plans for our future retirement after bringing up two sons who were leading very active lives and were ambitious for their future.

Helpline: 0808 800 2244
Email: helpline@headway.org.uk
Web: www.headway.org.uk



“Then everything changed overnight. We had to deal with the prospect of an unknown future for our son and ourselves. In 1994, brain injury diagnosis and treatment was not as advanced as it is today.

“Now, more than two decades later, we are acutely aware that as we get older, our ability to continue to give 24/7 support will become more challenging. We realise that things will eventually have to change and that our son will continue to need support when we are no longer able to give it.

“Our advice would be to explore what options may be available in your area. This is likely to be difficult given the fast-paced changing circumstances of health and social care that is currently taking place.

“Involve other members of the family and, most importantly, include the brain injury survivor in any discussions and decisions as they are the one that will be affected in the future.”

As a charity, we rely on donations from people like you to continue being able to provide free information to those affected by brain injury. To donate, or find out how else you can get involved with supporting our work, visit www.headway.org.uk/get-involved.

If you would like to leave feedback for this publication, please consider completing our short survey at www.surveymonkey.co.uk/r/hwpublications or contact us at publications@headway.org.uk.

Last reviewed 2023. Next review 2025.

Helpline: 0808 800 2244
Email: helpline@headway.org.uk
Web: www.headway.org.uk