Headway
the brain injury association

Ageing carers

for brain injury survivors

This publication discusses the concerns that ageing carers of brain injury survivors may have regarding their loved one's future care arrangements.

It offers considerations for planning the survivor's future care and suggests helpful sources of support and guidance when making these arrangements.

www.headway.org.uk
0808 800 2244

Introduction

Carers of brain injury survivors are often responsible for tasks such as managing finances, making appointments, preparing meals and providing transport for the survivor.

Many carers are conscious of how key their role is in the survivor's life. They may therefore have concerns about 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 main, and often only form of support available to a survivor. It can be difficult to know where to start with making suitable arrangements.

Talk to the survivor

When thinking about future arrangements, talk to the brain injury survivor and ask them if they have any questions. They might have concerns or fears of their own, and it is important to be able to discuss these and give reassurance where possible.

Have these conversations when you are both feeling calm, well rested, relaxed and are likely to not be interrupted.

Consider writing notes from your discussion, if this will be helpful for the survivor to refer to later (for example if they have problems with remembering or processing information).

Have short, regular discussions rather than one single, long discussion. This might be more helpful if the survivor struggles with fatigue or concentration.

Consider the types of care you are providing

Consider making a list of the types of care that you are currently providing, that someone will need to take over in the future. For example, helping the survivor with washing and dressing, preparing meals for them, arranging transport, taking them to appointments, managing their finances or providing emotional support.

Reflecting on this can help with making future arrangements, as you can consider who would be best placed to take over each of these aspects of care.

Talk to family and friends

Start having discussions with family and close friends about your thoughts around arranging future care. They may have advice to give or they may offer to help. Doing this also helps you to feel emotionally supported with what can typically be a difficult thing to think about.

Even if your family and friends cannot help out with specific tasks, ask if they can help in smaller ways such as helping with shopping, bringing cooked meals over or having regular phone calls with the survivor to ‘check in’. It might be possible to set up a schedule so that people take turns with helping out.

Consider deputyship

If you are acting as a deputy for the survivor, start thinking about who may be able to take over this role in future.

Ultimately, it will be up to the Court of Protection to decide on the replacement, but you can start to consider who may be good to approach for this and find out how they feel about the

possibility of making an application to become the survivor's deputy in the future.

This is a big responsibility with serious legal implications. The person should know the survivor well enough to be able to make decisions in their best interests. They should also be over 18 years old and should understand what deputyship is, as well as well as what their responsibilities will be.

Consider sharing information with them from the UK government's website on this topic at www.gov.uk/become-deputy.

Write a will

Make sure that you have a will in place. Writing a will ensures that your wishes regarding your assets (money, property, etc) are guaranteed to be fulfilled. It can also help to make sure that the survivor is provided for in the future.

You should always get legal advice when writing a will, especially when leaving money to someone who is dependent.

For more information on writing a will and how you can leave a gift to Headway in your will, visit our website.

Research local services

Find out about support that local social services can offer to the survivor and the process for making these arrangements. For example, they might be able to advise on housing arrangements such as support within the survivor's existing home or alternative accommodation.

Speak to other carers

Other carers of brain injury survivors may have similar thoughts or concerns about future care arrangements. They might therefore be able to offer helpful advice.

You can find out if your local Headway service has a carer's group where you can meet other carers.

You may also be able to get advice from other carers through carer organisations such as Carer's UK.

Visit care providers

If the survivor will not be able to live independently in the future, they may need to move into a residential unit or supported living facility. Consider looking into services nearby and visiting them in advance. This can give some peace of mind that you are choosing the right place for the survivor, as well as giving them a chance to visit the accommodation beforehand themselves to share their thoughts.

Write a future care plan

Write down any plans and arrangements that you would like to be considered in the future into a document called a 'future care plan'. Include information that the survivor and others will need to be familiar with in the future.

Keep this document in a safe place and review it every so often to make sure 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.

"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, many years 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 in the fast-paced changing circumstances of health and social care that is currently taking place."

We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2023.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

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helpline@headway.org.uk

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