Ageing carers

Introduction

Carers of brain injury survivors can typically 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 typically comprising 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 factsheet 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, always start off by speaking with the brain injury survivor and finding out what concerns they have. They might have fears of their own, and it is important to be able to openly discuss these.

Even if the survivor lacks capacity or has problems with information processing, involving them in these discussions as much as possible is very important. Naturally this should be done in a way that is appropriate and sensitive to the survivor so as to not instil a sense of concern or fear.

Talk to close friends and family

Sometimes talking to people close to us can help with managing our internal thoughts and relieving emotional stress or worry. Consider talking to close friends and family about the survivor’s care in the future. Even if you don’t have plans in mind just yet, starting to have these discussions early on can help to make sense of what can otherwise be a difficult thing to even think about.
Make informal arrangements
Talk to family and friends about unofficial ways in which they can help out in the future. Consider making informal arrangements, for instance you could ask family members and close friends to each commit to ringing or taking the survivor out on one day a month.

Consider who will take over deputyship
If you are acting as a deputy for the survivor, meaning you are legally responsible for making decisions in their best interests, start thinking about who you would trust to act as a deputy in the future. This is a big responsibility, and it is important to carefully select someone that you trust.

If there is someone who you feel would be reliable with this responsibility, start having this discussion with them and see how they feel about it. You should also guide them to the UK government website (www.gov.uk) to find out what being a deputy would entail and the steps they would need to take to apply for deputyship in the future.

More information about deputyship is available in the Headway booklet 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 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. More information on writing a will is available on the UK government website at www.gov.uk/make-will.

Headway offers a free will writing service via its Friends of Headway scheme; for more information on this visit www.headway.org.uk/donate/a-gift-in-your-will.

Inform other services
If the survivor is vulnerable, inform your local social services team and police. They may be able to make arrangements to ensure the safety of your loved one, for instance if they need assistance while out and about.

You should also consider applying for a Brain Injury Identity Card to help with these situations. For more information on the ID card, visit www.headway.org.uk/idcard.

Other sources of support and advice
Your local Citizens Advice would be a good place to start when seeking general advice on making practical future arrangements. You could also contact the Headway helpline for
Information and support on 0808 800 2244 or helpline@headway.org.uk.

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.

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-changing circumstances of health and social care that are 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.

Conclusion

It can be a difficult thing to think about and plan for the future, but for ageing carers of a brain injury survivor this can be unavoidable. It is hoped that the information in this factsheet has helped you as a carer to identify ways of making future arrangements for your loved one.

For more information about brain injury and its effects, visit our website at www.headway.org.uk/information-library.

Please tell us how helpful this publication has been by filling in our short survey at www.surveymonkey.co.uk/r/hwppublications.