



The challenge of caring

By Elaine Dowell, and reviewed by Alina Ellerington, Encephalitis International

Who are the Carers?

If you are the main person providing care to someone recovering from encephalitis, you may suddenly find that people are calling you the 'Carer' where before you were that person's wife, husband, parent, friend or child. You have got a new and highly responsible role, but it can take a long time to find out what that role means for you and for your family. It is important to acknowledge that this is likely to have a significant effect on you, and you too will need support.

It can take a long time, perhaps quite a few years, before you know how much your relative or friend will recover. In the early months you may have no idea of what the future holds, living from day to day, keeping an open mind and staying hopeful. You may find that you are grieving for the person as they used to be, while being happy that they have survived. You may be wondering what services are available to help you in your new role and how to access them. Maybe there are children to bring up, a job to do or worries about lost income.

Coping with the consequences of encephalitis can be highly stressful for the whole family. Spouses may have the added stress that they have no-one to share their role with. In dealings with those providing and planning services, make sure that they take the needs of the whole family into account, and that they take them seriously. You may feel as though you are being a nuisance, or demanding. However, professionals should understand that it is in everybody's best interests if the family is supported as a whole, and the individual needs of all family members are taken into account.

Understanding the effects of encephalitis

When your relative is saying something irrational, difficult or challenging, step back, take a deep breath, and think about what is behind it. How much do you know about your relative's injury and the effects it has on thinking, information processing, remembering, mood and ways of expression?

A child recovering from encephalitis may have a number of special needs, in terms of education, social, emotional and functional development. Unfortunately, the support for your child may not always be there and you may find yourself becoming the primary expert and advocate for your child. This may be in addition to bringing up other children. While you may not want to take on the role of a therapist, and it may be inappropriate to do so, that extra understanding can help you steer a smoother path through the hard times, and can be really helpful to your relative and the whole family.

It is important that you gather as much information as possible about the encephalitis and its difficulties by asking the professionals involved, Encephalitis International and any other voluntary organisation. Getting in touch with other people/carers of people affected by encephalitis and sharing experiences may help alleviate feelings of loneliness.

Carer's rights

- **Carer's Assessment** of your own needs and/or respite care if you are age 16 or above and provide a "regular and substantial amount of care" for someone age 18 and over. The assessment is provided by the local authority. They decide what type of help and support you need based on your personal circumstances. More information about the assessment is available on Carers UK website www.carersuk.org/carersassessment
- **Financial help** such as Carer's Allowance, Carer's Credit, help with council tax help with fuel cost, help with NHS health cost, budgeting loan and other help from the local authority. Detailed information about all this financial help is available on Carers UK website www.carersuk.org
- Parents of disabled children under 18 and carers of an adult who is a relative or lives at the same address as the carer have the right to request **flexible working arrangements**. However the employer is not bound to grant these requests, but they must give business reasons to justify the refusal of these arrangements.
- All employees have the right to take a 'reasonable' amount of time off work to deal with an emergency or an unforeseen matter involving a dependent.

How Encephalitis International can help

Encephalitis International provides help and support through these difficult times by offering the following services:

- Helpline +44 (0)1653 699599. This is manned during office hours Mon Fri 9-5, but there is an answerphone for out of office hours and callers can be called back at a time that suits them. Alternatively you can email your enquiries at support@encephalitis.info
- “Connection scheme” a scheme putting people in similar situations in touch with each other.
- Team Encephalitis Support Volunteers who have been trained and accredited by the Encephalitis International to provide local support.
- Encephalitis International’s meetings and events which may be day or weekend events.

Other sources of help

- Most GPs surgery run a ‘carer support group’ or have connection with a council-run carer information service.
- Carers UK have information about the practicalities of caring and ways in which you can ask for help (www.carersuk.org)
- Carers Trust provide access to desperately-needed breaks, information and advice, education, training and employment opportunities (www.carers.org)
- ‘Coping with Acquired Brain Injury. A Carer and Family Guide’ by Headway Ireland http://www.headway.ie/download/pdf/carerguide_redraft.pdf
- ‘The Selfish Pig's Guide to Caring’ by Hugh Marriott (ISBN0954423313) available to buy from Amazon (www.amazon.co.uk)

Support our information

With our support, no one has to face encephalitis alone. Our advice and information is available free of charge to everyone affected but we are truly grateful when supporters feel able to contribute a little to the cost of these resources. Please make a donation today by visiting www.encephalitis.info/donate or text ENCE11 followed by an amount (£1, £2, £3, £4, £5 or £10) to 70070.

Thank you!

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like more information on the source material the author used to write this document please contact Encephalitis International. None of the authors of the above document has declared any conflict of interest which may arise from being named as an author of this document.

Encephalitis International, 32 Castlegate, Malton, North Yorkshire, YO17 7DT, UK

Administration: +44 (0) 1653 692 583 **Support**: +44 (0) 1653 699599

Email: mail@encephalitis.info **Website**: www.encephalitis.info

Encephalitis International is the operating name of the Encephalitis Support Group.

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