What we think about: End of life care

What we think

Sadly, stroke continues to be a major cause of death. It is the fourth biggest killer in the UK, with someone dying every thirteen minutes from the condition. That’s why it is important to understand, and deliver, high-quality end of life care for those whose strokes are likely to be fatal. It’s also important that there is proper support for their families.

We know people with cardiovascular diseases, including stroke, tend to receive poorer end of life experiences compared to those who die from cancer. Research suggests this may be in part because it is difficult to predict the outcome for stroke patients, as it is normal for their condition to vary in the days and weeks following their stroke. This means identifying stroke patients who should be on an end of life care pathway can be very complicated, so it is important that care is individual to each patient and is reviewed regularly.

Clear, sensitive and regular communication between doctors, nurses and patients (if possible) and their families is essential throughout this process. This helps those affected to make informed
choices about ongoing care. End of life care for stroke patients must also reflect the possibility a stroke patient may not have the capacity to make these decisions.\(^7\) If a patient is unable to make a decision about care, doctors are ultimately responsible for decisions but should talk with family and friends to best understand what the patient would want.\(^8\) It is important that medical staff carefully explain to family and friends the likely impact of the stroke and the level of recovery the stroke patient could expect. Any decisions about care must be in the best interest of the patient.\(^9\)

Where patients are able, they should have the opportunity, with their family and friends, to discuss, decide on and regularly review an advanced care plan.\(^10\) This plan anticipates how their stroke may affect them in the future, where they want to receive treatment (at hospital, at home or in a hospice), as well as how they want their symptoms to be managed.

All stroke teams caring for end of life care patients should be encouraged to work with palliative care specialists, where this is appropriate. Currently, most stroke patients are not accessing specialist end of life care.\(^11\) But research has shown that when stroke teams work with palliative specialists, patients and their families are given more opportunities to discuss and decide on future care. This can improve overall end of life experiences for stroke patients and family and friends.\(^12\)

National strategies are in place in all four UK nations to improve end of life care and prevent areas of poor care.\(^13\)\(^14\)\(^15\)\(^16\) We support these strategies and call on health and care leaders across the UK to put services in place to support stroke patients on an end of life care pathway, as well as their family and friends.
What do we want to see?

- All stroke patients, their families and carers continuing to be given clear information around their condition and ongoing care options, and support to interpret and act on this information.

- All stroke patients on an end of life pathway being given the opportunity to access specialist palliative care.

- Governments working with CCGs, STPs, health boards and health and social care trusts to implement end of life care strategies.
What are we doing?

• We will continue to work in partnership, through coalitions, to advocate for better care for stroke patients on an end of life care pathway.

• Our national helpline will continue to give information to stroke patients and family and friends about end of life care, as well as signposting them to dedicated end of life care organisations.

• Where commissioned, our Stroke Recovery Coordinators provide support to families and signpost to specialist end of life services.

• We will consider in our next corporate strategy how best to address the needs of stroke survivors and their families approaching end of life, including the role of research and policy.
References

5. National End of Life Care Intelligence Network (2013) What we know now
11. http://spcare.bmj.com/content/2/Suppl_1/A14.1
When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

Contact us

We’re here for you. Contact us for expert information and support by phone, email and online.
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