

# Predicting decline and survival in severe acute brain injury: the fourth trajectory

**T**hree illness trajectories have been proposed to conceptualise how function declines as diseases advance to death: a short decline as with cancer; an episodic decline as with heart failure; and a prolonged decline as with dementia (fig 1).<sup>1 2</sup> These frameworks allow patients, family members, providers, and healthcare planners to prepare for next steps as they confront the limits of modern medicine and to develop compassionate healthcare systems that allow patients to live, age, and die with self respect and grace.

None of the existing trajectories is suitable for patients with severe acute brain injury,<sup>3</sup> a distinct group of neurological catastrophes for which the patient and their families are typically unprepared. Examples include vascular brain injury (both focal as with stroke and global as after cardiac arrest); inflammatory brain injury (infectious and non-infectious); and traumatic brain injury. Patients present acutely neurologically devastated and face a trajectory that often results in either early death or a more uncertain prognosis that may resemble the chronic disease trajectory with prolonged dwindling.

Although the exact number of patients affected by this heterogeneous group of diseases is unknown, the numbers of deaths worldwide every year from stroke (6.7 million), sudden cardiac arrest (3.7 million), and traumatic brain injury (>1 million) suggest that their contribution to both death and adult disability are large enough to warrant

attention.<sup>4-6</sup> Improved emergency response services and advances in acute and critical care management across all of these conditions, are likely to increase the numbers of patients surviving the initial period. Adopting a fourth trajectory for these patients (fig 2) could help prepare providers, patients, and their families to make more informed and critical decisions about care.

## Importance for surrogate decision makers

Because patients with severe acute brain injury are typically too impaired to express their preferences, decisions about goals of care and treatment options need to be made by surrogates—the family members and physicians—based on the patient's presumed wishes and estimated prognosis. These decisions have a big effect on survival and quality of life (box). Although differences exist internationally about who can be a surrogate decision maker, the need to be sensitive to the ideas of the family and caregiver as well as knowledge of the person is important whatever the setting. The choice is often between giving only comfort measures, which usually results in rapid death, or to give aggressive care, which holds out the possibility of life but with serious neurological impairment.<sup>3</sup> In contrast to the other three trajectories, which all end in death, the trajectory for patients with brain injury may end with the chronic stage of recovery. In this case survivors' trajectories are reset, they may survive for long periods, and the pattern of their death may follow any of the other trajectories.

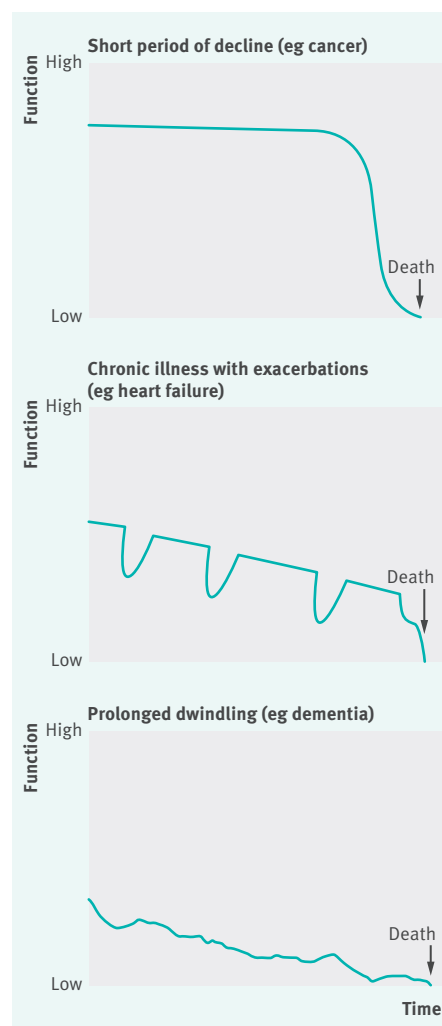


Fig 1 | Trajectories of chronic illness<sup>1 2</sup>

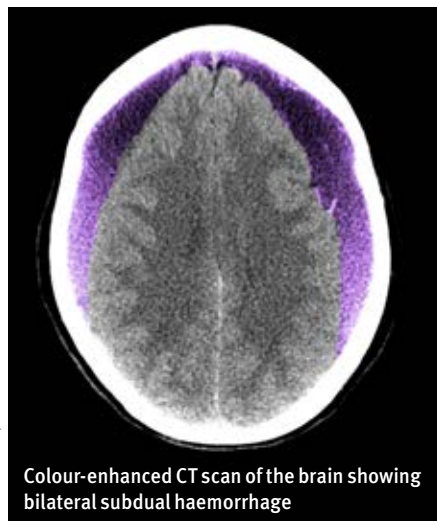
## KEY MESSAGES

Severe acute brain injury can arise from vascular or inflammatory disease or trauma and has a different trajectory from other chronic conditions

The acute presentation and prognostic uncertainty, along with the patient's inability to participate in treatment decisions, create distinct challenges

Providers need to acquire skills to help patients and families contribute to rapid, life altering treatment decisions

Healthcare systems worldwide need to be prepared for early deaths and prolonged survival and to encourage preference sensitive care



Colour-enhanced CT scan of the brain showing bilateral subdural haemorrhage

## Implications for clinical practice

Severe acute brain injury challenges care providers with a unique set of clinical care issues. The suddenness of the injury and the "time is brain" imperative create a fast paced, often chaotic environment characterised by uncertainty, fear, and stress for patients, family members, and care providers. Decisions must be made rapidly, unlike the case for patients with cancer and other chronic diseases, when goals can be clarified in the context of relentlessly progressive symptoms and disability.

Patients who survive the acute stage enter a chronic stage of recovery, when the chaos gives way to an agonising watchful waiting period. The potentially long disease course and changing function demand vigilance for emerging symptoms. Understanding this

Illness trajectories depicting how function declines to death with certain diseases, such as cancer, can help with palliative care. **Creutzfeldt and colleagues** propose a fourth trajectory is needed for patients with severe acute brain injury to improve decision making and standards of care

pattern and providing clear communication may help improve clinical care by considering the steps set out in the trajectory (fig 2).

### Building trust in crisis

When patients present with severe acute brain injury providers must quickly develop a trusting relationship with patients and their families. The first meeting should focus on this partnership and set the stage for future decision making. The patient, family, and healthcare team must simultaneously prepare for survival or decline, perhaps

to death,<sup>7</sup> a model of care balancing a “hope for the best” with “preparing for the worst.”<sup>8</sup> This uncertainty is challenging to communicate. One common recommendation is to start the conversation by giving a warning—for example, “I have difficult news for you.” Use of “I wish” statements helps acknowledge the provider’s limited control regarding the outcome,<sup>9</sup> such as “I wish I had more answers for you” or “I wish we could predict with more certainty.”

Virtually all communications are through surrogate decision makers. Because recovery to previous brain function is not a realistic option, patients and their caregivers will need to adapt to a new disability and new social roles. Proactive, periodic meetings with the family may help foster shared deliberation and decision making.<sup>10</sup> These meetings provide an opportunity to gather evidence about a patient’s acceptable levels of function, critical abilities, and tolerable and intolerable health states. It may be helpful to acknowledge the burden that surrogate decision makers carry, to reassure the family members of your support for them and the patient, and to commit to preventing and treating pain and other discomfort.<sup>11</sup>

### Decision making

Several challenges to decision making exist, particularly in the first few days after severe acute brain injury when the risk of death is greatest, the chance of neurological recovery most promising, and the treatment decisions most consequential. Elements that complicate decision making include the wide range of potential neurological outcomes; biases that lead to an overly pessimistic or optimistic prognostication<sup>12</sup>; patients’ inability to communicate their wishes directly; and the potential for

conflict between and within providers and family members. Compounding these challenges, treatment and care involve multiple providers (emergency physicians, critical care physicians, neurologists, neurosurgeons, cardiologists, geriatricians, palliative care physicians, and rehabilitation specialists) across many settings (emergency department, intensive care units, hospital, acute rehabilitation unit, nursing home, hospice). Conflicts may result from information gaps, confusion about treatment goals, emotions, mistrust, and genuine value differences.

Given these challenges and uncertainties, provider teams need expertise in understanding the implications of the neurological injury and the expected time frames of recovery, which vary by mechanism, severity, and location of injury. We recommend that decisions to withdraw treatment should not be made until at least some time has elapsed to allow for better assessment of prognosis. However, as physicians lead these early conversations towards decisions to minimise or maximise life sustaining treatment, they need to accept the uncertainties and communicate the range of potential outcomes. Depicting a “best case scenario” can help the family to weigh treatment burden against the hope for future improvement.

It is important to revisit discussions periodically to reaffirm or revise goals and treatment preferences, but decisions to withhold or withdraw life sustaining treatment after severe acute brain injury can typically not be

changed later. When appropriate, a second opinion may be helpful before deciding to withdraw treatment to improve the precision or clarify the imprecision of the estimate.<sup>13</sup>

### End of life care

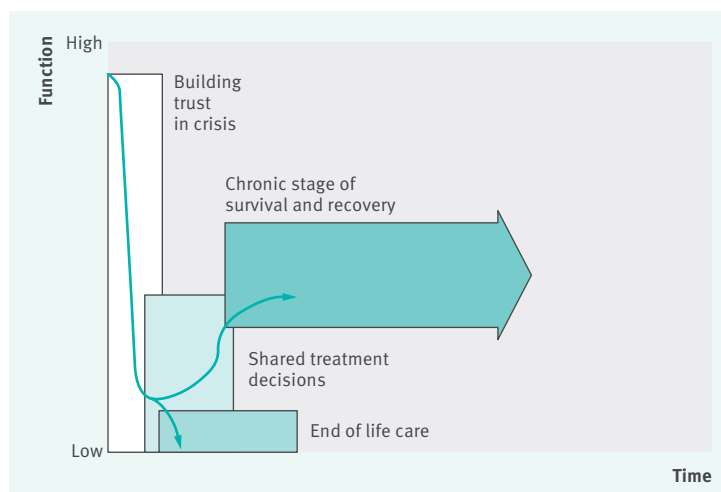
Most patients who die from stroke do so after a decision has been made to withhold or withdraw life sustaining treatment. Treatments that may be limited include artificial nutrition and hydration, intubation and mechanical ventilation, brain surgery, antibiotic treatment, or vaso active support.

Anticipatory guidance for the family is essential to help relieve anxiety and prepare for the withdrawal and dying process. This guidance should include communication about signs, symptoms, and expected timing of death; the removal of monitors to ensure a quiet environment; and available treatments to relieve pain and discomfort.<sup>14</sup> Withdrawal of life sustaining treatment is not withdrawal of care. Rather, it is a change of treatment goals towards ensuring comfort and relieving symptoms as the patient moves gracefully towards a peaceful death.

### Chronic stage of recovery

Although few longitudinal studies of recovery with multiple assessments exist, rough time frames to reach the chronic stage of recovery after severe acute brain injury range from 3-6 months for a cardiac arrest or stroke<sup>15</sup> to 1-2 years for severe traumatic brain injury.<sup>16</sup> Early survivors have varying degrees of disability and disorders of consciousness. Although patients may improve, medical complications and comorbidities may dwindle reserves and

### Teams need expertise in understanding the implications of the neurological injury



**Fig 2 | Trajectory for severe acute brain injury—patients present with a crisis that may result in early death (often after a decision to withdraw life sustaining treatments) or survival with a high degree of disability**

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can lead to sudden or progressive decline in function and cognition. Periodic setbacks, decreasing function, increasing dependence,<sup>15 17</sup> and an inability to maintain hydration and nutrition may lead some towards the trajectories seen with chronic illness with exacerbation or prolonged dwindling.

### Implications for health service delivery

In a system geared towards shorter hospital stays and faster discharges, we still need to allow time for a clearer prognosis to emerge, for families to understand the illness, and for opposing views to find a middle ground. Hospitals as well as nursing homes or rehabilitation

facilities should be prepared to allow an elegant movement between life sustaining treatments and comfort measures. One way to enhance patient care, provide consistent communication, and minimise conflicts across care settings might be to set up longitudinal provider teams, organisational structures, and data systems that monitor patients over time and evaluate performance along the continuum.

Performance measures could also be used to encourage best practice. In addition to assessing adherence to evidence based management in severe acute brain injury, such as dysphagia screening after stroke, and avoidance of harm, such as thromboprophylaxis, new measures

should be developed to reflect this fourth trajectory. These could include, for example, assessment of the extent to which patients and families report understanding of key facts of decisions and the extent to which management seemed consistent with loved ones' preferences. Given that death from severe acute brain injury often occurs after a decision to withdraw life sustaining therapies, death rates may be related to the quality of preference sensitive care rather than effectiveness or safety.

Future research should explore ways to help providers and families predict patient preferences for treatment and establish measures of the quality of decision making, including levels of agreement among the participants. Research is also needed to develop interventions that improve long term care and health related quality of life after severe acute brain injury, such as in-home rehabilitation and nursing programmes as well as home based educational interventions and caregiver support to help keep patients out of hospitals and nursing facilities and increase their time at home.

### Conclusion

Severe acute brain injury threatens what many people consider their essence. The presentation is sudden and unexpected; the prognosis is uncertain and ranges between death and survival with a wide range of disabilities; and the long term outcome relies on early, rapid treatment decisions, virtually all of which are with surrogate decision makers and across various care settings and provider teams.

Our proposed fourth trajectory will help ensure that as healthcare systems shift their focus towards performance measures, medical care efficiency, and financial stewardship, patients and families receive timely, transparent, individualised, and balanced information in a culturally competent manner such that treatment decisions are optimally aligned with fully informed choices.

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### EXAMPLE OF SEVERE ACUTE BRAIN INJURY TRAJECTORY

This previously healthy man in his late 50s suddenly developed global aphasia and dense right hemiplegia. He became sleepy as brain swelling developed as a result of a large stroke in the distribution of his left middle cerebral artery. Clinicians recommended to his wife that he have an immediate decompressive hemicraniectomy, and all eventually agreed to proceed despite uncertainty about whether his zest for life would endure when he was faced with severe, likely permanent, neurological deficits. After the life saving surgery, waxing and waning mental status, pneumonia, and a urinary tract infection complicated his hospital stay and recovery. Two weeks after the event, he was still unable to swallow safely; his clinicians and wife agreed to place a feeding tube surgically into his stomach.

On discharge to the nursing home, he was awake but unable to talk. He seemed to recognise his family members but did not follow commands or vocalise. His entire right side remained paralysed. One year later, he is living at home with his wife. He is able to eat and walks short distances. He has started speaking a few words, saying "no" quite emphatically, as well as "yes" and "honey."

He is able to interact with his loved ones and seems to have no regrets. His wife believes the correct decisions were made and values the time with her husband despite his limited abilities. Another patient and another family member in the same situation may not have wanted to choose survival at all costs. Our challenge is to help individual patients and their families navigate their illness trajectory as they identify their own goals of care and then match the treatment provided to those goals.



Severe acute brain injury threatens what many people consider their essence