

Coordination of care and post-sepsis support

Model of Care Framework

ARTD Consultants, Sydney (Eora), Melbourne (Narrm) and Brisbane (Meanjin), prepared this report on behalf of the Australian Commission on Safety and Quality in Health Care

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Preface

On 13 September 2019, the Hon Greg Hunt MP announced \$1.5 million in funding, to support improved sepsis outcomes. The Australian Commission on Safety and Quality in Health Care (the Commission) established the National Sepsis Program in June 2020 under a contract for services with the then Department of Health and Aged Care.

Priorities for coordinated national action on sepsis were identified through consultation with The George Institute for Global Health (TGI), state and territory health departments, sepsis clinical experts and healthcare organisations.

These priority areas formed the basis of the program's key objectives, which included:

- Improving the recognition of sepsis in all healthcare settings
- Providing healthcare professionals with nationally agreed sepsis clinical guidance materials
- Strengthening the comprehensive care planning process for sepsis survivors.

The Commission, in partnership with TGI delivered eight discrete projects including in 2022 the launch of the first National Sepsis Clinical Care Standard.

The 2022-23 Budget provided a further \$2.1 million to continue a focus on improving sepsis recognition and response. The Department engaged the Commission in partnership with TGI to deliver the National Sepsis Program Extension between 2023 and 2025.

The Program Extension is made up of five additional projects:

1. Targeted national public awareness campaign
2. Education and training resources for healthcare professionals
3. Coordinated sepsis care and post sepsis support for survivors and families.
4. Data collection tools for quality improvement
5. Improving recognition of sepsis in First Nation peoples.

Aim

The coordinated sepsis care and post sepsis support project aims to provide greater information and clarity for consumers, their families and healthcare professionals about options and pathways for high-quality evidence-based coordination and post-sepsis care.

The Commission contracted ARTD consultants to evaluate the implementation of care coordination and post sepsis support in health care services, recommended in the sepsis clinical care standard, and to define key elements of an effective model of care to strengthen coordination of post sepsis information and support, including bereavement support. ARTD consulted with sepsis survivors, families and health workers to develop a Model of Care Framework that describes the principles and processes to support local conversations about what is needed to strengthen quality and safety and drive continuous improvement in sepsis care coordination and post sepsis support.

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Australian Commission on Safety and
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Acknowledgements



We also acknowledge the talent and artistry of Emma Walke, who designed the artwork for our acknowledgment of Aboriginal and Torres Strait Islander peoples. The design shows a story of connection to country and people, representing the breadth of work we do with Aboriginal and Torres Strait Islander communities across Australia. The colours represent the land, and the lines in between represent the water that connects us all.

This work was completed with the assistance of the National Sepsis Program at the Australian Commission on Safety and Quality in Health Care, and Dr Brett Abbenbroek from The George Institute for Global Health and Sepsis Australia.

We would also like to thank the many key informants from the hospital and health sector, as well as sepsis survivors, their families and carers, and people bereaved by sepsis. We thank them for their time and insights and trust that their views are adequately represented in this report.

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Contents

1. Introduction to the Framework -----	7
2. The Model of Care Framework-----	9
Guiding principles for care -----	13
3. References -----	17

1. Introduction to the Framework

In 2022-2023 there are over 84,000 separations of sepsis survivors from Australian public hospitals, and over 12,000 in-hospital deaths.¹

People with lived experience of sepsis and healthcare professionals recognise that there are gaps and inconsistencies in care coordination and support for sepsis survivors, their families, carers and people bereaved by sepsis.

This **Model of Care Framework for coordination of care and post-sepsis support** has been developed to guide health services across Australia as they implement the [Sepsis Clinical Care Standard](#) (2022) to improve sepsis prevention, recognition and response. The Standard provides national clinical guidance to support health providers improve early recognition, treatment, outcomes and post-discharge support for people at risk of or diagnosed with sepsis in Australia. Quality Statements 4-7 (QS 4-7) of the Standard focus on coordinated in-hospital care, patient and carer education and information, transitions of care, and care after hospital and survivorship.

The Model of Care Framework focuses on providing high-value healthcare across each stage of the sepsis journey. It has been developed by ARTD Consultants on behalf of the Australian Commission on Safety and Quality in Health Care (the Commission), and The George Institute for Global Health (TGI) and Sepsis Australia as part of the National Sepsis Program Extension.

This Model of Care Framework is supported and accompanied by a:

- Business Case outlining a cost benefit evaluation
- Supporting Evidence and Implementation Ideas document.

These resources can be found on the Commission's website.

"I was basically discharged, told go and find this from your local pharmacy once I could... But then I fell down the stairs that night pretty much and ended up back in hospital basically just because I had no idea what was going on... I was also on an antibiotic for four weeks but I had no idea why." – sepsis survivor, focus group

The Framework is not intended to be a fixed, one size fits all approach. The gaps and opportunities for service improvement identified in this and the **Supporting Evidence and Implementation Ideas**, and **Business Case** companion documents can be addressed in many ways, for example:

- by embedding care coordination and post-sepsis support functions within existing roles, processes and governance
- by incorporating care coordination and post-sepsis support functions within other existing complex care services
- by resourcing a specific role or roles.

This Model of Care Framework provides the principles and processes to support local conversations about what is needed to strengthen quality and safety and drive continuous improvement in sepsis care coordination and post sepsis support.

Regardless of the ways in which the model is implemented locally, it is important to address coordinated care across all transitions of care through the patient journey, including post-sepsis care in the community.

2. The Model of Care Framework

An Australian framework for care coordination and post-sepsis support will enable health services to deliver on the National Health Reform Agreement² and achieve the quintuple aims of health care: improving the health of populations, enhancing the patient experience of care, reducing the per capita cost of health care, improving the work life of healthcare providers, and advancing health equity.³ This is outlined in Figure 1.

Figure 1 Theory of change

IF WE

Provide access to coordinated care and post-sepsis supports

Address gaps in education and training about sepsis and post-sepsis syndrome

WE CAN ACHIEVE

Early recognition and treatment of sepsis and post-sepsis syndrome

Coordination and collaboration through transitions of care

Improved communication between consumers and medical professionals

LEADING TO

Improved patient understanding of and adherence to medical advice after discharge

More efficient and effective use of primary health

Reduced preventable hospitalisations

Reduced trauma for bereaved family members

OVER THE LONGER TERM CREATING

Faster recovery times and outcomes

Improved health, wellbeing and socio-economic outcomes

Reductions to the costs of providing health care.

The two figures below show how the Model of Care Framework considers the journeys of sepsis survivors and their carers and families (Figure 2), and of people bereaved by sepsis (Figure 3). They outline the elements, activities and behaviours required to provide effective care coordination and post-sepsis support.

The models emphasise strong **transitions of care**, to minimise quality and safety risks associated with systemic gaps. At the centre of the frameworks are the **principles of care**.

The framework contains several elements:

- **Principles:** represent the core of what people with lived experience of sepsis want from their healthcare providers. **Focus on listening, communication, collaboration, open disclosure and empathy.**
- **Transitions of care:** describes the critical points of transition through the health system where improvements in coordination of care are needed. **Focus on information, communication and transitions of care.**
- **Better care initiatives:** describes elements of care coordination, post-sepsis support and bereavement support, which, overall, are not yet consistently delivered, and where continued development is needed. **Focus on information, communication, planning, collaboration and coordination.**
- **Key clinical priorities:** are system activities undertaken within the system to ensure a consistent standard of care but currently delivered in an ad hoc or inconsistent way. They are often reliant on an individual's knowledge or practice. **Focus on systematisation and integration in hospital and primary healthcare settings.**

Figure 2 Sepsis model of care for sepsis survivors

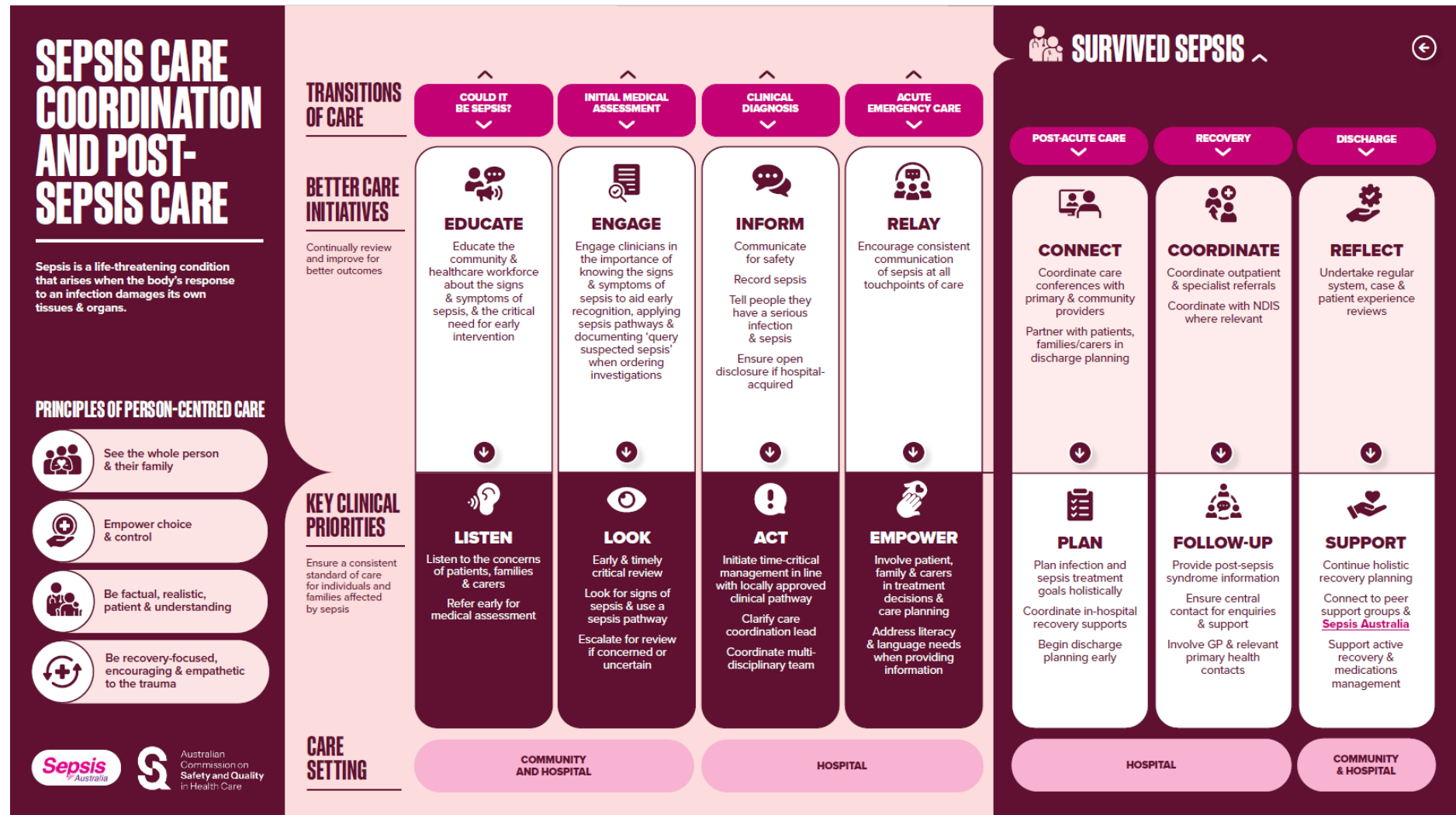
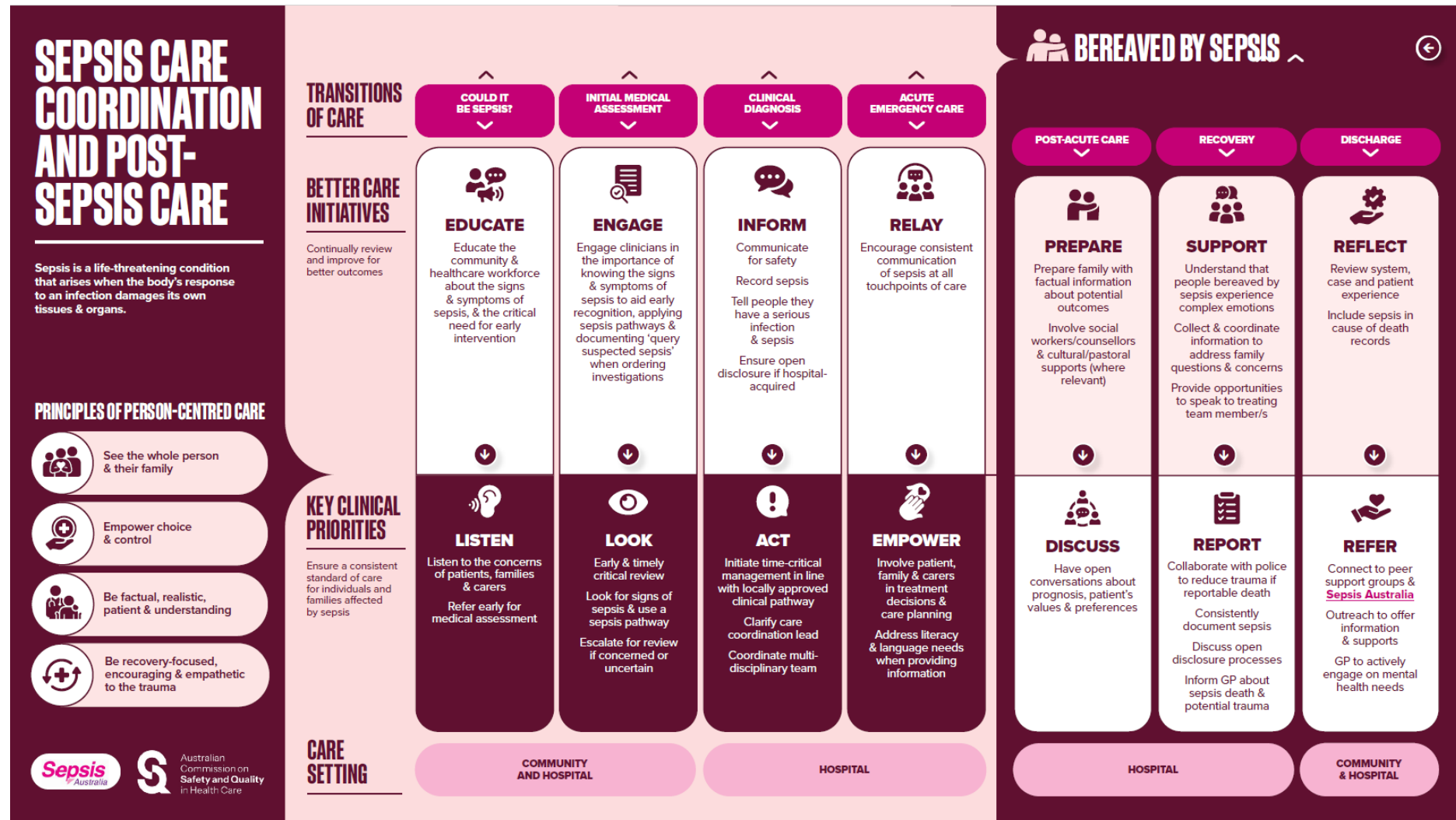


Figure 3 Sepsis model of care for people bereaved by sepsis



Guiding principles for care

Detailed descriptions and examples of the principles highlight what is important to consumers.

Sepsis patients, their families and carers

See the whole family: this means understanding what behaviour is normal for a patient (which may rely on family or carer input); understanding a person's health and capabilities prior to sepsis, which is important to inform recovery goals and treatment; understanding the person's spiritual and cultural beliefs; providing holistic care post-sepsis (i.e. broader than a clinical focus).

This also means understanding the formal and informal networks around a person which could include their family, friends, carers, workplace or school. These are people who may be able to provide the treating team with information, who can be active participants in recovery, or who may also need information to help them support survivors.

Empower choice and control: consumers want treating professionals to practice deep and active listening, with non-judgemental curiosity, to enable better responsiveness to their concerns. They want health providers to empower them to be involved in decision making throughout the sepsis journey, especially through care transitions, and when planning for recovery and survivorship. This includes providing information to enable informed decision-making and self-care. Conversations about preferences around resuscitation and end of life should also take place early.

Be factual and realistic, patient and understanding: consumers want information on the risks and the potential impacts of sepsis, without these being softened. This includes information on the risks of sepsis, treatment, and potential symptoms and impacts experienced post-sepsis.

"Post-sepsis syndrome is real and varied and the patients and advocates need to be believed when they say the effects are not the patient's normal behaviour." – family member of sepsis survivor, survey

"We all start as being an independent person who can make our own decisions without any support and then you end up in this situation where effectively that gets taken away from you, and then you try to get that back again. Through this process [of creating a model of care] we're trying to get the patient to have the choice and control they need as much as they can, every step of the way." – sepsis survivor, focus group

"I want more explanation of what 'not well' means – if we had known what to look for we would have pushed for [family member who died] to have been seen sooner." – person bereaved by sepsis, interview

Consumers want care teams to be patient with them, take the time to explain what is happening, what might be expected in the future, and to be patient in responding to their concerns. They also want their treating professionals to understand that they may be experiencing shock, fatigue, feelings of vulnerability and overwhelm. They may also experience confusion or memory loss or be grieving or adjusting to new expectations about their future. Sepsis survivors, families and carers want health professionals to understand how much fear they live with around the potential for sepsis to reoccur.

Recovery-focussed and encouraging: consumers stressed the importance of an encouraging and recovery-focussed approach, and of having goals for care and recovery.

"In hospital, my surgeon spent an hour with me after my amputations, explaining the long and arduous journey ahead, how patience would be rewarded and suggesting ways to work with my modified limbs to achieve the goals I still adhered to." – sepsis survivor, survey

People bereaved by sepsis

See the whole family

When there is a loss from sepsis, it is often traumatic. This can affect the bonds between family members. It is important that both the needs of individual family members, and the family unit are supported through the dying and grieving process. It may be appropriate to refer bereaved family members to individual mental health or counselling supports as well as to family counselling services.

This is especially important for families who have lost a child to sepsis. Parents who have lost a child are more likely to leave employment, get divorced and experience mental health issues.⁴

Bereaved siblings are at a higher risk of negative physical and psychological outcomes than their peers.⁵ In instances where a child or young person is losing or has lost a sibling, parents or carers may find it very helpful to have a professional explain what has happened in an age-appropriate way. A child or young person's community, which may include school, sporting and community groups, religious institutions, and friendship groups can also be informed to create a circle of support.

"[My family is] fragmented and dysfunctional. No-one offered support, so we all just had to make our own way. We don't talk about it... I still don't really know what happened. Mum cannot talk about it so I cannot discuss it with my family. I am on my own. None of my friends understand. I am trying to manage in isolation." – person bereaved by sepsis, interview

"My ex-husband [and I] divorced. So then I was a single parent, and I was working full-time. All my grief had to just be parked." – bereaved parent, interview

Empower choice and control

Empowering choice and control in the context of end of life and bereavement can look like:

- consulting the family about the patient's values and preferences, including cultural preferences around end of life
- asking family members during end of life and after death how much information they want or need
- offering information to family members in different formats
- giving family members opportunities to ask questions, including offering this at a later date
- providing a calm and confidential space in which to have conversations with police acting on behalf of coronial processes
- providing support options, including information about hospital bereavement services, other services and peer support groups
- providing options to access information and support in locations other than the hospital where the person died.

End of life and palliative care disciplines have a range of relevant resources and education opportunities, including toolkits, that could be useful.

Be factual and realistic, patient and understanding

Having realistic conversations about a person's prognosis is important in helping families prepare and make decisions about dying and saying goodbye.

A person with sepsis can sometimes go from being well to dying very suddenly and it is normal that families will have a lot of questions. Providing factual information about what has happened is very important to help them make sense of the experience. This includes using the word sepsis. They may not be able to take in information at the time of the death but may want it later.

Patience and understanding from health professionals about families' need to understand exactly what has happened is essential to supporting people bereaved by sepsis to process the death of their loved one.

Be empathetic to the trauma

People bereaved by sepsis want healthcare workers and others involved, such as police, to acknowledge their loss and the traumatic circumstances. They want health professionals to understand that the speed and lack of knowledge about sepsis prior to losing a loved one creates a traumatic and often bewildering experience. It leaves people with questions, and a desire to talk about what they have been through with others who have experienced the loss of a loved one to sepsis (i.e. through connection with peer support groups).

Some people experience guilt that they did not know about sepsis, notice the signs or act more quickly. It is important that healthcare and social workers/counsellors understand this and can respond in a way that reduces self-blame.

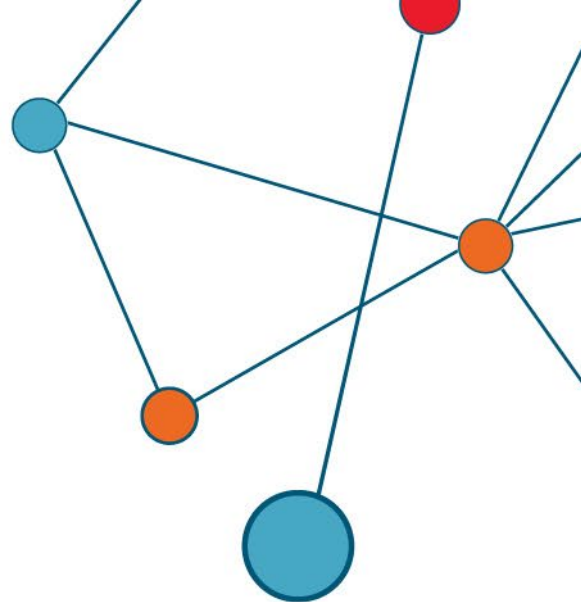
Care should focus on providing the right supports and connections to process the circumstances of the death they have experienced and recover from the trauma of losing a loved one to sepsis.

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