Implementing a paediatric sepsis program in partnership with families affected by sepsis

Queensland Paediatric Sepsis Program, QLD

Sepsis is a life-threatening illness that occurs when the body’s response to infection injures its own tissues and organs. In 2017, more children died from sepsis in Queensland than from road traffic accidents or leukaemia. Sepsis has become a global and national priority.

When a child is diagnosed with sepsis, families are often overwhelmed by confusion and uncertainty. As they struggle to understand the unfamiliar condition and its lifelong impacts, they report feeling confused about the meaning of their child’s diagnosis and isolated from their family and other support systems. They often feel a need for unique support and guidance that no one in their existing personal or hospital care teams can provide.

Alana English, an Advanced Social Worker with the Queensland Paediatric Sepsis Program (QPSP), says, “When we’re talking to families, some time after the death of their child, they say, ‘I don’t know what sepsis is. People keep using this word ‘sepsis’, but I have no idea what it means.’ It is frightening to me that their child has died from sepsis and there is still so much confusion about what that means.”

Much has been achieved in Queensland over the last five years to improve the care of children at risk of sepsis. This includes the support for families with children recovering from sepsis, or those having lost a child to sepsis. This work included the development of a paediatric sepsis pathway across Queensland hospitals, as well as an extensive program for consumer engagement and resource development.

In 2018, Meagan O’Keefe, Advanced Social Worker within the QPSP, conducted a series of focus groups with families who had a lived experience of paediatric sepsis. The goal was to understand their sepsis journey and their unique support needs. The QPSP Family Support Structure was developed in response to the feedback gained from these focus groups and continues to evolve.

“One of the key messages from families in terms of the presentation of sepsis, and I think these words are very resonating, is that it’s rapid, it’s visual and it’s shocking. Shocking in terms of the amount of trauma that’s involved. Shocking in terms of how quickly their child can go from a healthy child to an extremely unwell child, and potentially a child that passes away. It is shocking how quickly that can happen.”

Alana English, Advanced Social Worker, Queensland Paediatric Sepsis Program
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The resources and programs developed by the QPSP and families can now be found on Queensland Health’s Sepsis in Children website, launched in 2021. The website also includes a link to the QPSP Family Support Network (FSN).

Additionally, the Sepsis in Children website provides clinicians with current evidence-based practice resources and education for paediatric sepsis. The multimodal education platform, developed by QPSP Clinical Nurse Consultant, Amanda Harley, supports clinicians to learn and enhance their ability to recognise and deliver paediatric sepsis care. Available resources include posters, factsheets, case study presentations, amongst other educational resources for local hospital adaptation. The platform allows hospital educators, quality and safety teams, managers and clinicians to easily embed paediatric sepsis education into curriculum and their department, aiming to raise awareness of paediatric sepsis in their services.

What changes were made?

QPSP Family Support Structure

The QPSP Family Support Structure is an evolving model of care that aims to provide key resources and programs to support the child and family at all points of their journey. A key strength of this structure is the co-design by consumers and, in part, delivery by consumers. Currently, the Family Support Structure includes:

- **Family Support Network** enabling families who have a lived experience of sepsis to be well supported, connect with others with similar experiences, access useful information and resources, and be actively involved in QPSP’s research, resource development, and media opportunities.

- **Peer Mentor Program** providing support for families with a child recovering from sepsis, or bereaved as a result of sepsis, by linking them with peers who have a lived experience, for a minimum of six months. The program aims to provide families with the unique understanding, encouragement and support which only another parent who has walked a similar path can provide. The program can be offered to any family within Queensland as the support is provided via phone and email.

- **Journeying through Sepsis**, a video series to support families with a child who has survived sepsis, providing information and guidance on each stage of their child’s hospital journey, from initial diagnosis through to intensive care, rehabilitation and support after discharge. Key messages are provided primarily by families from both metropolitan and rural areas, and clinicians working in this specialist area.

“We all play a part to decrease the morbidity and mortality associated with paediatric sepsis. At the centre of this, is the united vision to attend work, perform well and do no harm to optimise outcomes for children diagnosed with sepsis.”

Amanda Harley, Clinical Nurse Consultant, Queensland Paediatric Sepsis Program
• Identification of the differing needs of Aboriginal and Torres Strait Islander families and families from Culturally And Linguistically Diverse (CALD) backgrounds so that they can be addressed in culturally appropriate ways. The appointment of an Aboriginal and Torres Strait Islander Lead to work collaboratively with the QPSP is the first step in this extension of the Family Support Structure. A range of the QPSP resources have been translated into 10 different languages, with the assistance of the Refugee Health Council.

Queensland Health Paediatric Sepsis Pathway

Queensland Health introduced a new state-wide Paediatric Sepsis Pathway to support improved recognition, escalation and overall management of children with sepsis, or at risk of sepsis.

• The pathway includes a treatment bundle consisting of antimicrobial therapy, lactate and blood culture sampling, followed by fluid bolus and consideration of inotropes.

• Family resources are also embedded in the pathway, including a ‘Could this be sepsis?’ parent leaflet that provides basic information about sepsis, a checklist of symptoms, and a link to further resources. The leaflet is designed for parents and carers who are taking a child home from hospital after treatment for any kind of infection. It encourages families to be aware of the signs of sepsis and to return promptly if they have concerns. The leaflet carries an important message of empowerment for parents and carers, encouraging them to trust their ‘gut feeling’ or ‘intuition’ when they feel something may not be right with their child. These messages are reinforced by posters throughout ED settings.

• Professional training and dedicated sepsis roles including sepsis co-ordinator roles, help raise awareness of the new pathways and resources to support implementation and education. Training is available in a variety of formats to meet the needs of health settings and staff, and contributes to Continuing Professional Development (CPD) points.

Queensland Health Sepsis in Children website

QPSP developed Queensland Health’s Sepsis in Children website as a central hub for both families and clinicians. It provides families with access to a range of resources and programs developed by the QPSP and families, and connects them with others who have experienced sepsis. And it provides clinicians with up-to-date and evidence-based education on paediatric sepsis.

At a Glance

Issues

• Low awareness among parents and carers
• Limited empowerment of parents and carers to advocate for their child
• Lack of support structures and resources for families with a child diagnosed with sepsis, or bereaved as a result of sepsis
• Limited engagement and understanding of needs and supports required by Aboriginal and Torres Strait Islander families and Culturally and Linguistically Diverse families
• No paediatric sepsis pathway or education material for use across Queensland

Solutions

• Family Support Structure with multimodal resources and support programs including written resources, videos, Family Support Network, Peer Mentor Program and opportunities for advocacy and input into program and resource development
• Development of clinical pathways and education materials for children with sepsis, including family-informed resources

Barriers

• Lack of awareness and education in families
• Change-fatigue in workforce
• Competing quality improvement projects
• Overall fatigue in health workforce due to COVID impacts

Enablers

• Co-design processes to ensure family supports meet family needs
• Consumer representation and involvement in multiple aspects of QPSP, including Clinical Advisory Group, Peer Mentor Program, Family Support Network, pathway and program development workshops
• Communication and training to support implementation of new pathways and care bundle, tailored to meet the local needs of clinical and nursing staff
• Online resources with clear guidelines including the Paediatric Sepsis Pathway Implementation framework and toolkit
How were changes supported?

- New sepsis-awareness and sepsis-education materials and programs for families were co-designed by families who have lived experience of paediatric sepsis through various codesign workshops, focus groups and meetings with the QPSP.
- Training programs to aid the implementation of the new clinical pathways and resources are tailored to match the needs of the health setting and its workforce. This includes addressing any specific barriers identified by the workforce, running shorter or longer sessions as necessary, and making online training modules available to support flexible learning.
- Communication and training for clinicians emphasises key benefits including that the new pathways are more patient-centred; that new resources, including the parent leaflet, will make discharge processes easier, more effective and efficient. Information provided to parents will limit potentially problematic self-directed ‘Dr Google’ searches by parents.
- Communications and training for nursing teams emphasise key benefits including that the new resources can be used by nurses to help escalate their concerns in situations where escalation to a medical officer may be challenging.
- To help embed new knowledge and new practices in a positive context, the launch of training, pathways and new resources are accompanied by fun activities including festive food and social quizzes.

Outcomes

- A survey of Emergency Department nurses identified that departments with a funded sepsis champion, and factors associated with confidence, skills and environmental context, had a positive association with median knowledge scores.
- An observational study to evaluate the implementation of the new paediatric sepsis clinical pathway in 12 Emergency Departments in Queensland indicated that compliance with the paediatric sepsis bundle of care for children admitted to the Intensive Care Unit improved, from 27% to 58% within 60 minutes of recognition, and from 47% to 75% within 180 minutes of recognition.

Quality statements

1. Could it be sepsis?
5. Patient and carer education and information
7. Care after hospital and survivorship

Read more about the Quality Statements in the Sepsis Clinical Care Standard:
safetyandquality.gov.au/sepsis-ccs

More Implementation Studies

Read more about the implementation of improvements in sepsis care:
safetyandquality.gov.au/sepsis-implementation
- Embedding Antimicrobial Stewardship in sepsis care
- Delivering better sepsis care in regional and remote communities

Resources

- Sepsis Clinical Care Standard
- Parent Factsheet in Queensland Paediatric Sepsis Pathway
- Sepsis website
- Journeying through Sepsis video series
- QPSP Family Support Network
- QPSP Peer Mentor Program
- Paediatric sepsis education for health professionals
- Translated sepsis information resources for families