

# Optimising health outcomes for children living with Haemophilia in rural communities

by forging partnerships between  
Haemophilia Treatment Teams and Local Health Networks

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It is well documented that the further children live away from specialist treatment the poorer their health outcomes and with vast distances in Australia meeting the needs of children with haemophilia in rural areas can be impeded<sup>1</sup>. Overcoming barriers in each community is important including the identification of key personnel to partner with families and the establishment of a network of local health professionals that are accessible to provide optimal support and care. Achieving improved health outcomes for children with haemophilia requires an adaptive and collaborative approach and when outreach care for two young boys with severe haemophilia was required, the

Regional care: South East Regional Community Health Service, Millicent



South East Regional Community Health Service (Millicent) undertook this challenge.

## Goals

The goals for care provision were to:

1. provide a safe environment including immediate access to prophylaxis and treatment for bleeds as well as support in an unfamiliar environment
2. reduce the anxiety and burden on the families that were caring for these boys thus enabling them to remain in their rural community
3. provide education and support to the community health nurses to achieve the immediate and longer-term goals including prophylaxis infusion via peripheral access and implanted venous access device, establishing a treatment plan for bleeds, prevention of bleeds and independence for families
4. provide education and support to the wider community engaging with these families including local school and hospital staff and general practitioners.

Community health nurse teaching carers to access implanted venous access device and administer treatment



## Strategies utilised

Due to the distance from Adelaide (450 km) education was initially provided to a key clinical nurse at the Millicent Community Health Service via telephone with further resources for educating other staff and families sent via email.

Regular phone contact was established to help carers identify bleeds and what to do if they occurred. It was important to develop a plan for educating families about haemophilia and time the release of information to not overwhelm or burden the families.

The haemophilia specialist nurse from Women's and Children's Hospital visited the region and the Haemophilia Treatment Centre (HTC) provided education and support to school personnel, carers, GPs and community health nurses.

A training program was established for the extended community nurse team and hospital staff through 1:1 education, small group sessions by the key clinical nurse leading to a regional education session for 20 nurses run by HTC staff.

Ongoing support and access to the haemophilia specialist nurse, with continuing education on longer-term goals were provided via phone and regular email contact as well as 24-hour access to support from HTC via the inpatient haematology ward and on call haematologist.

## Role of key Clinical Nurse in the region

### Education of local health care team on:

- > what is haemophilia is how it is treated
- > understanding treatment goals
- > IV cannulation and VAD access
- > reconstitution of Factor VIII products and infusion
- > how to recognise a bleed
- > how to access Factor VIII supplies

### Establishment of:

- > BloodSafe recording
- > after hours treatment plan utilising local
- > knowledge of services available
- > access to local policy and procedures

### Education of children with haemophilia and their carers:

- > What is haemophilia and what does this mean for the daily activities of a child with haemophilia?
- > Bleed recognition and treatment.
- > Prevention.
- > How to access health care in the area.



Independence: A child with haemophilia managing his own treatment

## Outcomes

- > Staff knowledge improved and confidence increased to manage haemophilia care.
- > Family confident in care and support network.
- > Independence in treatment of child with haemophilia.
- > Decreased presentations for bleeds.
- > Lower school absentee rates.
- > Minimised impact of haemophilia on family.
- > Children remained in their rural community.

## Discussion

The key to achieving optimal care was the close and open communication between specialist nursing staff in the HTC, the local community nursing team and family networks. Providing relevant education in a variety of formats and the opportunity to have these repeated by local staff ensured the sharing of information and broadened the exposure of the community to haemophilia care. The local knowledge of the staff was important to ensure local policy and procedures were established and implemented.

## Future goals

- > Improving access to treatment and services and specialist care in the region with specialised staff from HTC visiting the region for review clinics.
- > Improving knowledge of medical professionals in the region resulting in timely treatment for emergency care at local hospitals.
- > Establishing haemophilia link nurse positions in the region.

## Conclusion

Close partnerships between specialist haemophilia staff and local health service providers has been integral to improving health outcomes for children with haemophilia in the rural setting.

## Reference

Strong K et al 1998. Health in rural and remote Australia: the first report of the Australian Institute of Health and Welfare on rural health. Pg 6, Cat. no. PHE 6. Canberra: AIHW.



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