

The Nurse and Comprehensive Haemophilia Care

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Wide variation of roles

- Size of HTC
 - 1 nurse 7.5 hours per week
 - 2 full time nurses
- Structure of HTC
 - Independent/associated with other units
- Adult or paediatric or both
- Other team members
- Geography

Partner with patients & families

- Maximise quality of life
- Facilitate treatment
- Anticipate and prevent complications
- Advocate
- Navigate health system
- Listen and learn from patients and their families

Primary point of contact



Primary point of contact

- For patients and families
 - Assess bleeds & determine treatment
 - Link with other members of the team & community healthcare providers
 - Link with support groups, Haemophilia Foundation
- Telephone advice to all disciplines within hospitals and community agencies

Education

- Patients, families, carriers
 - Clinic, Workshops, HF Camp
- Prevent, recognise and manage bleeds
- Develop & review individual plan
- Genetic counselling
- Birthplan for carrier women



Home Treatment & Transitions



Assist patients and families to take control



Educate health professionals



Administration

- Develop and maintain systems to optimise care
- Registration of patients in ED/blood bank
- Guidelines and resources for staff
- Liaise with and provide resources for rural hospitals, GPs
- Haemophilia ID cards for patients

Surgery planning



Melbourne 1909

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Community Education

No  **h**

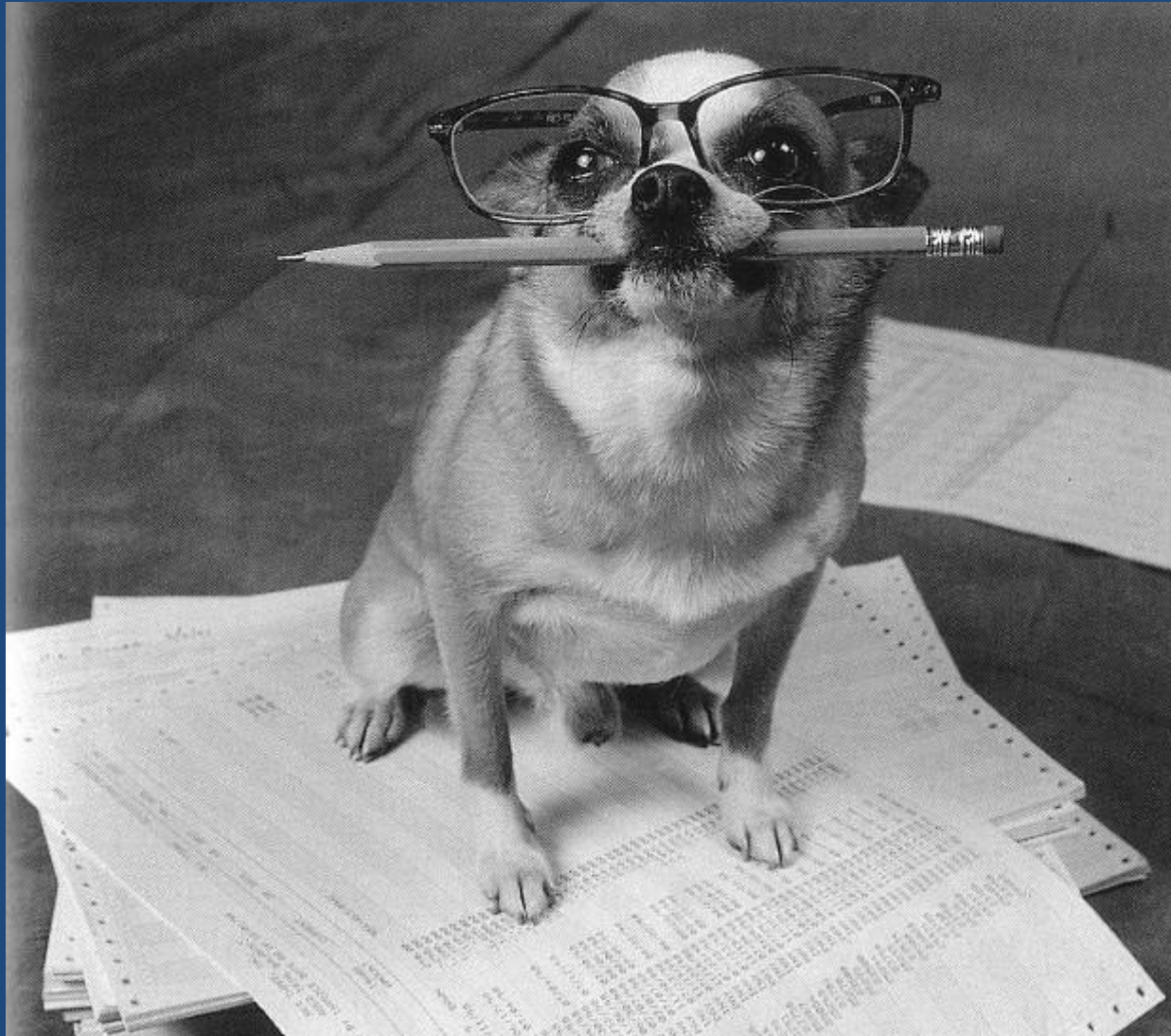
Help patients and families prepare for travel interstate and overseas



Clotting Factor Management

- Manage hospital and patient stock
- Work within hospital & other systems
 - Quality and safety
 - Blood bank
 - Pharmacy
 - Emergency Department
 - IT
- ARCBS
- Pharmaceutical companies
- National Blood Authority

Reporting, Research, Representation



Networking

- Network with other bleeding disorder professionals and Haemophilia Foundations
- Share knowledge and experience - via Australian Haemophilia Nurses Group
- Conferences
- Support by Haemophilia Foundations and Industry sponsorship

Challenges

