

Keynote Plenary Session Setting the scene – Using Evidence: Using Guidelines

Amyloidosis awareness

Ellen Reid*, Amyloidosis Australia, VIC

Clinical Practice Guideline	Guidelines on the diagnosis and management of AL amyloidosis. Members of the Guidelines Working Group of the UK Myeloma Forum on behalf of the British Committee for Standards in Haematology (BCSH).
Stakeholders	Doctors and nurses in the Haematology, Oncology, Cardiology and Emergency departments at The Alfred Hospital, Melbourne, Victoria. Doctors and nurses in the Emergency Department, William Angliss Hospital, Upper Ferntree Gully, Victoria. Amyloidosis patients and carers around Australia, and worldwide via the internet.
Evidence-practice gap	My late husband was diagnosed with AL Amyloidosis in 2001. We wanted him to have the best possible treatment in Australia where there are no Amyloidosis experts.
Implementation strategies	No detailed information about Amyloidosis was ever received from any of the doctors, so we searched the internet for help. There is an ACOR (Association of Cancer Online Resources) discussion group from whom we learnt that we had to be pro-active with the hospital staff. We used PubMed and Google to find articles, and a contact's on-line journal access to download PDF files.
Data	British Journal of Haematology Volume 125, Issue 6, Page 681-700, Jun 2004 We photocopied the Guidelines and had them inserted into my husband's hospital files. Photocopies were given to all his doctors and nurses.
Results	My husband's quality of life was improved, and his life was extended. Other patients have also received better treatment.
Barriers	Hospital staff who believed that Amyloidosis was incurable and untreatable were resistant to information that showed otherwise.
Enablers	My persistence. I carried copies of the Guidelines with me wherever we went for treatment.
Resources	I made time. My husband's life was at stake, and I loved him. Nothing was too expensive or more important than helping him survive.
Key message	Doctors do not have the time to search for information about rare diseases. Patients and their carers need to obtain the Guidelines for their condition, then read them, consulting medical dictionaries where necessary, and discuss them with the medical personnel.
* Presenter Bio	Mrs Ellen Reid, is a retired community Pharmacist with 35 years experience in Western Australia and England. She researched the plants used by Aborigines for medicinal purposes in W.A. in the 1970's. She retired in 1999 to become a full time carer for her husband. In 2005 she and her family started the first charity in Australia dedicated to helping Amyloidosis patients and their carers, Amyloidosis Australia Inc.

www.amyloidosisaustralia.org