

Myeloma Information Pathway

This leaflet is designed for healthcare professionals (HCPs) who provide information to those affected by multiple myeloma (MM). The aim is to help you identify the information needs of patients, caregivers (or relatives) in a timely manner as they go through different phases of the disease, and provide them with access to reliable sources of information. These third party information resources are recommended in addition to your local information resources.

Why is it important to keep patients informed?

Patients are becoming more active consumers of health-related information, which helps in disease prevention, promotion of self-care, informs treatment decisions, and improves the effectiveness of clinical care.^{1,2}

Patients should be encouraged to be well-informed and take an active role in obtaining and understanding information relating to their care to support their role in shared decision-making.

The right information at the right time

The amount and type of information individuals want varies according to their unique information needs, which in turn can vary according to the disease, its stage, the person's age, socioeconomic status, culture, and beliefs.¹

Patients with cancer often want information about their condition, and their satisfaction with this information is a significant predictor of quality of life. It is well accepted that newly diagnosed patients generally have the highest information needs, along with their caregivers.^{1,3}

For those who provide care to those affected by MM, the challenge is finding a way of providing information that is appropriate to the patient who may want to know something about their illness and its treatment, but may not wish to know everything about it at all times.

How patients and caregivers access information

As well as having differing information needs, individuals also differ in their preferences of how they want to receive that information.¹ Patients needs vary in terms of how much information they want, their ability to identify reliable information sources, and to understand the information presented.

Low health literacy can be a significant barrier to the equitable access of information and a patient's ability to make informed healthcare decisions.¹ This is an important consideration when deciding on the type and format information is presented, as a one-size-fits-all approach will not work.

HCPs are the most frequently cited information source and play a crucial role in meeting patients' information needs.² Increasingly though, patients and caregivers are accessing health information, via the internet. However, due to the variable quality of information, there is the potential for them to act on erroneous information, or become more confused.^{1,2}

To help patients discriminate, HCPs can play a role by directing them to reliable sources of good quality health information. In the clinic setting, information needs are often acute, and the availability of smartphone applications (apps) provides instant access to useful resources. For patients and caregivers, information needs are generally more chronic, so they can be directed to websites which they can visit as needed during their disease journey.⁴

STAGE 1: REFFERAL, INVESTIGATION, DIAGNOSIS, AND STAGING OF MM

- Signs and symptoms
- Tests and investigations
- Bone marrow aspirate & trephine
- Cytogenetics / FISH
- Imaging
- Blood & urine protein electrophoresis
- Haematology & biochemistry
- HCP contact details (e.g. main person / point of contact, allied health, specialist)
 - Include in/out of hours contact details
- Relationships, communication, and emotions
- Counselling / psychological support
- General information
- Social services
- Government organisations
- Patient support groups and organisations
- Healthy living / lifestyle / sexuality / complementary therapies
- Questions to ask your specialist

Suggested sources of Information:

myeloma.org.au
leukaemia.org.au
cancer.org.au
labtestsonline.org.au
nps.org.au
eviq.org.au

Consider international MM sites as appropriate.

STAGE 2: TREATMENT

- Active monitoring (MGUS / Asymptomatic MM)
- Treatment options - general and specific information relating to treatment regimens, disease comorbidities, and treatment toxicities
 - Chemotherapy
 - High-dose treatment with stem cell support (autologous / allogenic)
 - Immunomodulators
 - Proteasome inhibitors
 - Monoclonal antibodies
 - Steroids
 - Bisphosphonates
 - Radiotherapy
- Clinical trials
- Blood / platelet transfusions – procedure and side effect information
- Individual plan for follow-up
- Disease progression and relapse
- Active monitoring
- Rehabilitation care and physiotherapy
- Dietary and nutritionist support

Suggested sources of Information:

myeloma.org.au
myeloma.org.uk
myeloma.org
eviq.org.au
nps.org.au
australianclinicaltrials.gov.au
anzctr.org.au

STAGE 3: SURVIVORSHIP

- Late & long-term effects (Survivorship)
- Screening for early recognition and management
- Bone health
- Health maintenance
- Mobility & safety
- Sexual dysfunction
- Renal health
- Second primary malignancy
- Frailty, psychosocial issues, and rehabilitation
- Survivorship care plans

Suggested sources of Information:

b-s-h.org.uk
leukaemia.org.au
myeloma.org
palliativecare.org.au
myagedcare.gov.au
humanservices.gov.au
carersaustralia.com.au

STAGE 4: PALLIATIVE CARE

- Change in goals of care (palliative care)
- Community & hospital palliative care services
- Advanced directives and living wills
- Choices for end-of-life care
- Power of Attorney

Suggested sources of information:

palliativecare.org.au

SUPPORT THROUGHOUT THE DISEASE JOURNEY

- Patient support services:
 - not-for-profit groups
 - community and government organisations
 - peer-support groups
 - face-to-face or online
 - accommodation
 - transportation
 - access to benefits
 - services at-home
- Support services for carers
- Finance (work, funding treatment, hospital visits and transport, life and health insurance)

Suggested sources of Information:

myeloma.org.au
leukaemia.org.au
cancer.org.au
cancer.org.au
humanservices.gov.au
carersaustralia.com.au
myagedcare.gov.au

Sources of MM information for nurses and patients

This is a list of the most commonly used websites by healthcare professionals and patients.

Organisation	Website	Information
Myeloma Australia	myeloma.org.au	Australian organisation providing patient and HCP resources, including myeloma nurses, telephone support, and support groups, access to publications, live seminars and workshops. Links to Myeloma Scientific Advisory Group (MSAG) Clinical Practice Guidelines
Leukaemia and Blood Cancer NZ	Leukaemia.org.nz	Leading organisation in NZ dedicated to providing support to patients and their families living with MM and other blood conditions. Provides range of support and education programs, including online information.
Multiple Myeloma NZ	Multiplemyeloma.org.nz	MM focused organisation lead by haematologists and consumer representatives providing a range of MM specific information.
Myeloma and Related Disease Registry (MRDR)	Mrdr.net.au	Established at Monash University, Melbourne, MRDR is a bi-national register of patients diagnosed with MM and related conditions. Website provides information on the registry, how to participate, and reports/publications generated from the registry.
MyeNURSE	Member only app iOS / Android	Haematology Society of Australia and NZ (HSANZ) Nurses Group: Myeloma Special Practice Network member login required to access MyeNURSE app, which hosts wide range of MM nurse resources.
International Myeloma Foundation (IMF) - Nurse Leadership Board (NLB) and International Myeloma Working Group (IMWG)	themmrf.org	International organisation providing patient and HCP resources, including details of clinical trials, education programs and MM research.
Myeloma UK - Myeloma Academy	myeloma.org.uk academy.myeloma.org.uk	UK-based organisation providing patient and HCP resources, including updates on research, support groups, and discussion forums. Hosts Myeloma Academy which provides clinicians with a range of educational programs and resources, including the Myeloma Nurse Learning Program accredited in Australia for hours of learning.
Myeloma Beacon	myelomabeacon.com	US-based organisation providing patient and HCP resources, including news articles, patient forums and discussion, and blogs.
International Myeloma Society	myelomasociety.org	International professional society of clinicians and researchers, which organises biannual International Myeloma Workshop (IMW).
Managing Myeloma	managingmyeloma.com & iOS app	International organisation providing HCP resources and education.
Myeloma Crowd	myelomacrowd.org	International organisation that support patient-to-patient education.
Leukaemia Foundation	leukaemia.org.au/blood-cancers/myeloma	Australian organisation providing patient and HCP resources and information on blood cancers.
National Comprehensive Cancer Network	nccn.org	International organisation providing patient resources, HCP education, and treatment guidelines.
Cancer Institute	cancerinstitute.org.au	NSW cancer control agency providing patient information about cancer prevention, detection, diagnosis, and treatment. Portals for HCPs and consumers.
NPS MedicineWise	nps.org.au	Australian organisation providing patient and HCP education and information about medicines.
NZ medicines and medical devices safety authority	Medsafe.govt.nz	NZ government authority responsible for the safety of medicines and medical devices. Provides information for HCPs and consumers.
Lab Tests Online	labtestsonline.org.au	Australian organisation which explains pathology laboratory tests.
Cancer Learning	cancerlearning.gov.au	Australian government organisation providing HCP education and learning resources in cancer care.
EviQ	Eviq.org.au	Australian government organisation providing online resources on cancer treatment protocols.
Myeloma Post	Mobile app - iOS only (free)	Patient and HCP app with resources, education, research support, details of advocacy programs, and information on the IMF website.
The Myeloma Manager™ Personal Care Assistant	myeloma.org/patient-tools/myeloma-manager	Patient app that organises laboratory results, notes, reports, and provides a daily news feed.
Track My Multiple Myeloma	iOS and Android (free)	Patient app with calendar, HCP contact list, medication reminders, refill reminders, record lab results, printable reports, and resources.

Organisation	Website	Information
Cancer Society NZ	Cancernz.org.nz	NZ national not-for-profit organisation providing support and education programs for those affected by myeloma and other cancers.
Canteen	Canteen.org.au Canteen.org.nz	AU / NZ chapters of a not-for-profit support organisation helping young people cope with cancer in their family. Provides information, counselling, connections, and peer support as well as service directory, and supports research.
Cancer Council	Cancer.org.au Iheard.com.au	National not-for-profit support organisation providing a range of support and education programs for those affected by MM and all cancers. Range of programs to support cancer clinicians. <i>Iheard</i> by Cancer Council providing evidenced-based answers to commonly asked questions relating to cancer and its treatment.
Australian Clinical Trials	Australianclinicaltrials.gov.au	Australian government National Health & Medical Research Council site listing all clinical trials registered in Australia and a range of related patient educational resources.
Australian New Zealand Clinical Trials Registry	Anzctr.org.au	Online registry of clinical trials in Australia, NZ, and beyond.
ClinTrialsRefer Australia & NZ	Mobile App iOS and Android (free)	Provides listing of MM and haematology related clinical trials being undertaken in Australia and NZ. Search by region, trial status, and disease category.
Australian Government Department of Human Services	Humanservices.gov.au	Details about Centrelink and Medicare services.
Carers Australia	Carersaustralia.com.au	National peak body working with others to deliver a range of essential national carer services.
Palliative Care Australia	Palliativecare.org.au	National peak body for palliative care. Providing information, seminars for patients, carers and clinicians. Advocacy, policy and guidelines, and service directory.
Australian Government: My Aged Care	Myagedcare.gov.au	Government aged care system website and contact centre.
MacMillan	Macmillan.org.uk	UK cancer organisation dedicated to improving lives of those affected by MM and all cancers, through a range of support and education programs, advocacy, research and support of cancer clinicians.
Kidney Health Australia	Kidney.org.au	Patient organisation dedicated to helping people with kidney disease. Providing education, information and support.
British Society for Haematology	b-s-h.org.uk	UK Haematology professional group. Providing education, grants and guidelines, including those for MM and related haematological disease best clinical practice, including nursing care and interventions. Guidelines freely available online.

THE FOLLOWING LIST OF BLOOD AND BONE MARROW TRANSPLANT RESOURCES MAY BE USEFUL FOR SELECT PATIENTS / CLINICIANS

Organisation	Website
Myeloma UK (Transplant booklet)	myeloma.org.uk
International Myeloma Foundation (Transplant booklet)	myeloma.org
Australian Red Cross Blood Service	Donateblood.com.au
NZ Blood Service	Nzblood.co.nz
NSW Agency for Clinical Innovation Blood and Marrow Transplant Network (ACI BMT Network)	aci.health.nsw.gov.au/networks/blood-and-marrow-transplant/resources
NZ Bone Marrow Donor Registry	Bonemarrow.org.nz

AU: Australia; FISH: Fluorescence in-situ hybridisation; MGUS: Monoclonal gammopathy of undetermined significance; MM: Multiple Myeloma; NZ: New Zealand.

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