

Creating a National Resource – Parents, Health Professionals and Government working together to support children with palliative care needs and their families



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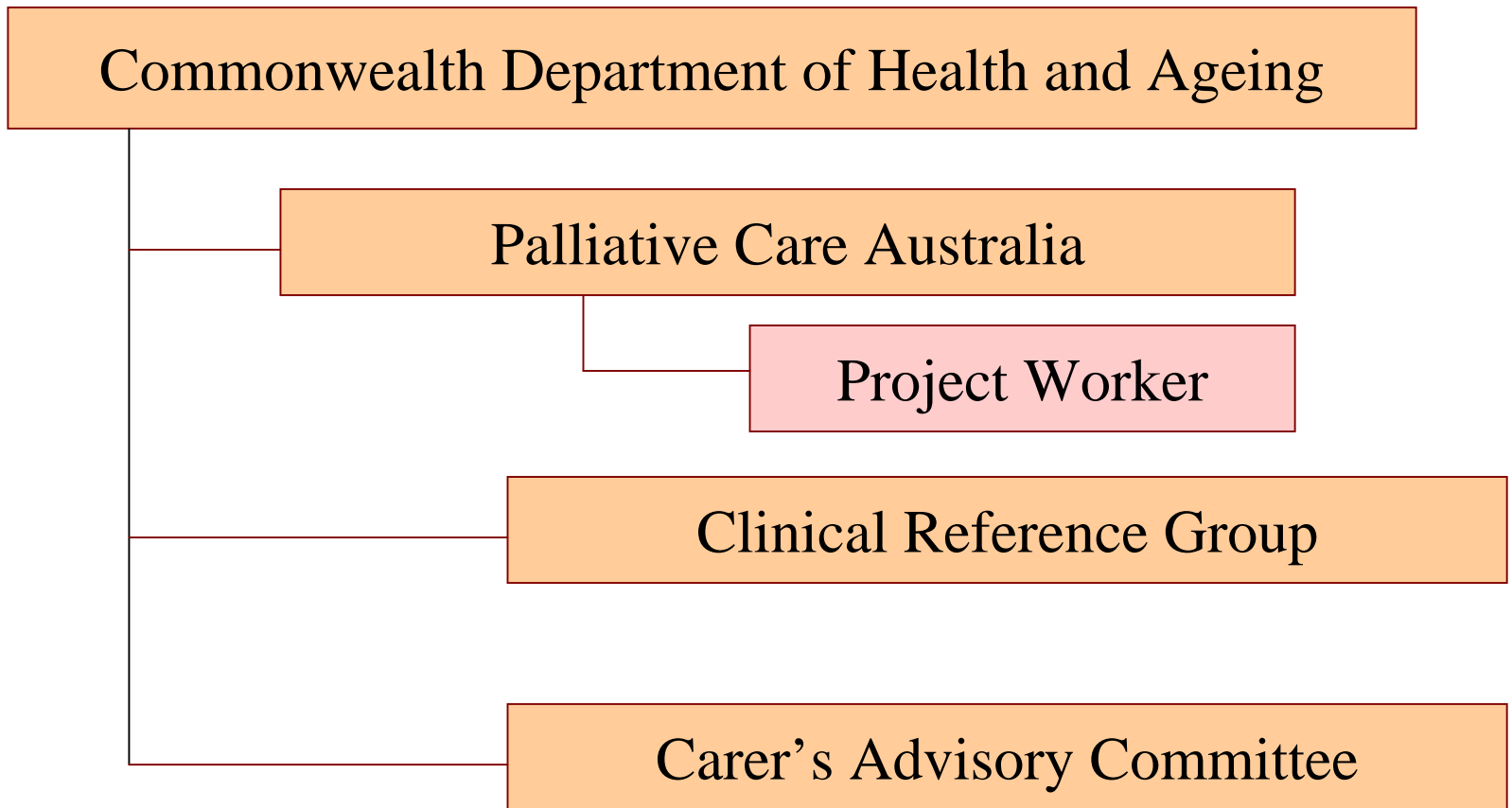


What is paediatric palliative care?

- "Palliative care for children and young people with life-limiting conditions is an *active* and *total* approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of *respite* and care through death and *bereavement*."

(Royal College Paediatrics and Child Health, UK)

Managing the “ Paediatric Resource Project”





Why develop a resource?

- National Palliative Care Program, Australian Government of Health and Ageing study (2004) into paediatric palliative care delivery in Australia identified:

“the provision of comprehensive and timely information about both clinical and management aspects of paediatric palliative care ... to provide families (particularly in rural areas), local health care professionals, community hospitals and other relevant organisations.”

Paediatric Palliative Care Model of Care Review – Final Report 2004

VPPCP/DoHA/PCA

22/2/07



Aim of the resource

- To provide quality information to dying children and their families and communities
- To enable children and their families to utilise the document in a timely fashion throughout their individual experience of the journey
- To ensure the resource is targeted at non-medical people across all areas of Australia, particularly rural, regional and indigenous



Consulting on the development of a resource?

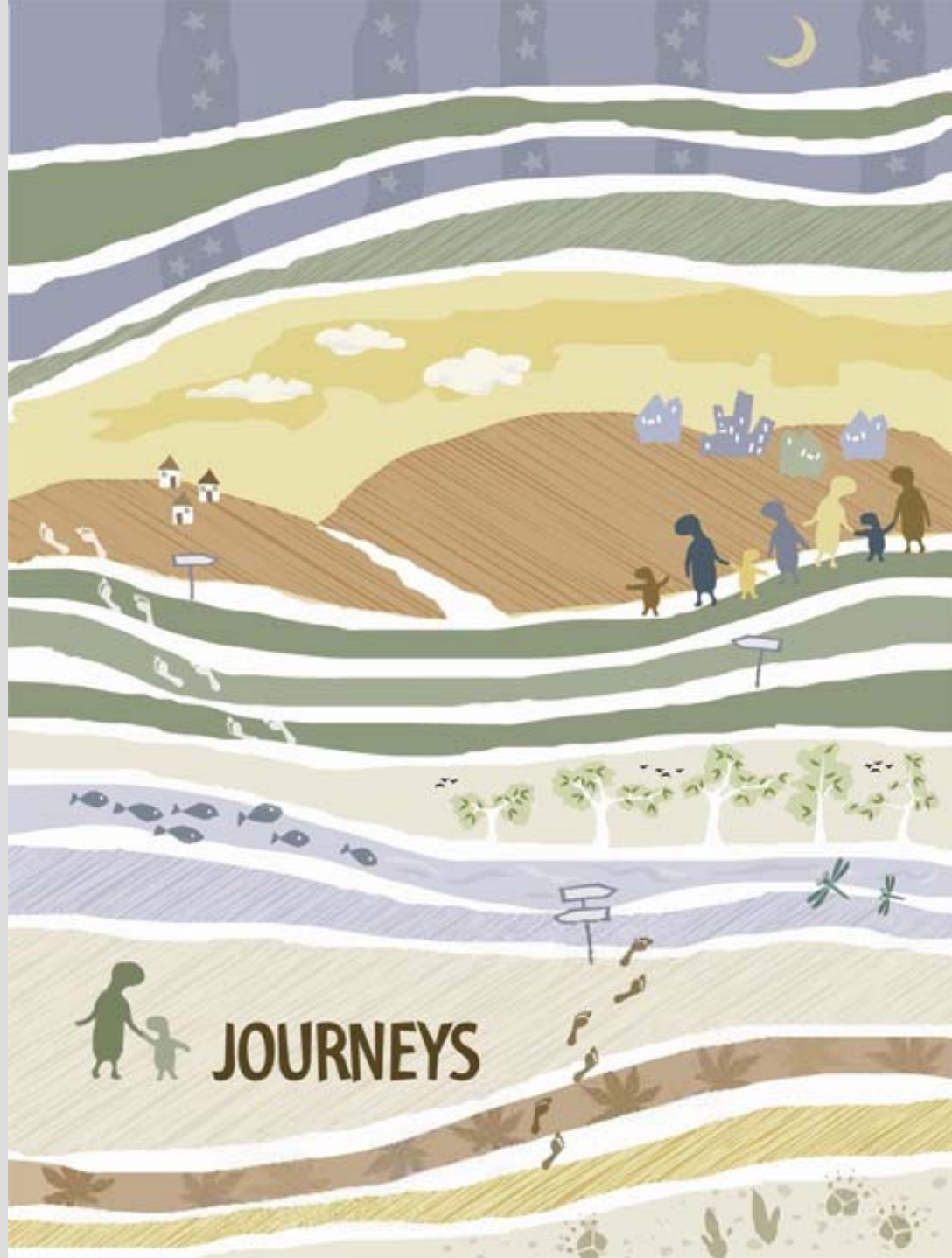
“Rather than relying on expert opinion about what is needed and how best to provide it, stakeholders must be consulted about *their* priorities and realities.” (MacPherson 2006)



Consulting on the development of a resource?

Consumers:

- “to act as a ‘reference group’ for consultation, providing an organized resource, clearly valued by ...staff and others to assess service users’ views.
- Comprise “... networkcommittee ... cross membership with a wide array of network and non-network, cancer-related and non cancer-related, local, regional and national groups” (A. Richardson et al 2005)
- “The failure to include a critical reference group of consumers and carers will create the unnecessary risk that the questions they consider most pertinent, through their own use or contact with the service **will go unmasked**” (Lammers and



JOURNEYS



The introduction outlines the **purpose** of this folder and encourages you to adapt the information to suit your own needs.

This section includes special notes for:

- families living in **rural and remote** areas
- families from **culturally diverse** backgrounds
- **Indigenous** families.

This section also includes **definitions** of words you may come across during your journey.

“We felt as long as we had some sense of control,
we could handle most things.”

“...endless nights of thinking, how are we ever going to
get through this?”

“We knew when something felt right for us.”





When your child is diagnosed with a suspected life limiting condition, your search for answers and information begins.

To help you prepare for what lies ahead, this section:

- looks at the **early information needs** many families have
- outlines what you can expect to receive from **palliative care**
- describes the **roles of the different health professionals** you may come across
- provides hints on how to **find reliable health information** about your child's condition and on understanding **treatment options**
- includes information about your **rights and responsibilities**
- provides information on accessing **financial support**.

"I wish we had understood palliative care better —
we would've used them more if we knew then what we know now."

"Who's going to help us?"

"You don't get information unless you know the right questions to ask."





As you learn more about your child's illness and see changes in their health and wellbeing, you are drawn further into your journey.

This section helps you find the best way forward by:

- exploring the **options and choices available in caring for your child**
- providing tips on **care planning** and **managing the symptoms** of your child's condition.

This section also focuses on **emotional support for your family**. It:

- describes the feelings of **loss and grief** that family members may experience
- contains suggestions for **recording special moments** with your family
- looks at ways for you to **support yourself, your children, your partner and other family members**
- contains advice about **seeking support** from those around you
- explores **spiritual issues**.

"Can we care for him at home? What will we need to do?"

"How can we best support our other children?"

"I felt hurt that some family and friends weren't there to support me."





For some families, their journey takes them to a place where they must confront issues concerning **dying, death and bereavement**. This section explores these sensitive issues and guides families along this unknown path.

This section includes chapters on **bereavement support, making memories and celebrating anniversaries**. It contains:

- suggestions for **talking to children about dying and death**
- information on **end of life decisions** you should consider
- options for **funerals**
- a brief description of the **dying process**
- detailed information about **what to do when your child dies**.

“We mostly felt torn — hoping for the best while preparing for the worst.”

“Our ultimate goal became to help our daughter die well and to help our son survive as a ‘whole’ person.”

“How do you know when the time comes?”



TIPS TO HELP YOU THROUGH YOUR GRIEF

TOOL FOR PARENTS AND GRANDPARENTS

- Take one day at a time.
- Be aware that everyone involved will react differently.
- Surround yourself with family and friends and those who will support you.
- Share your feelings with others. Find a trusted person to talk to about your child or grandchild.
- Try to be active and exercise.
- Avoid medicines such as sedatives — they can be useful for providing needed relief for short periods but should not be taken to avoid your grief entirely.
- Try to resist being rushed into big decisions, such as moving or changing jobs.
- Try to avoid activities that you don't feel ready for if well meaning friends try to help you 'feel better'.
- Set goals for yourself, e.g. do volunteer work for a charity or develop new interests.
- Maintain hope. You may find hope and comfort from those who have experienced a similar loss. Knowing some things that helped them, and realising that they have recovered and time does help may give you hope that sometime in the future your grief will be less raw and painful.
- Don't underestimate the healing effects of small pleasures as you are ready. Sunsets, a walk in the woods, a favourite food — all are small steps toward regaining your pleasure in life itself.
- Permission to backslide. Sometimes, after a period of feeling good, we find ourselves back in the old feelings of extreme sadness, despair or anger. This is often the nature of grief, up and down, and it may happen over and over for a time. It happens because, as humans, we cannot take in all of the pain and the meaning of death at once. So we let it in a little at a time.
- There is no time limit on grieving.
- Seek professional support if your grief becomes too intense.

MEDICINES LIST

Keep the medicines list up to date by crossing out any medicines stopped and adding new ones.
 Take it with you to each visit with your child's doctor, hospital, pharmacist and care team.
 Keep it with you at all times in case of an emergency.

Name		Weight	
Date of birth/Age		Allergies	
Contact names		Contact details	

Name of medicine (Brand or generic name)	Strength/form	What is medicine for?	How much to use and when?	Special instructions	When to start/when to review	Possible side effects Discuss with care team
Example: Amoxicillin	125mg/ml Syrup	Urine infection	5ml, 3 times a day	Give every 8 hours approximately, Use syringe measure.	1 Nov 2005, review in 2 weeks	Diarrhoea Mouth thrush

List all medicines currently used including: prescription medicines, over the counter medicines, herbal and natural treatments.




Medicines come in different forms: tablets, liquids, capsules, inhalers, drops, patches, creams, suppositories, injections, drips.

Adapted from the Medicines List — get to know your medicines

RESOURCE SET

SECTION 1 — INTRODUCTION

Welcome to the resource set for Section 1 of *Journeys — Palliative Care for Children and Teenagers*. In this set you will find a list of resources which includes reading material titles, organisation names and contact details, and other information.

The aim is to make it much easier for you to find additional information and support. The symbols    are used to illustrate whether the resource is found by phone, book or website/email.

It is important that this information is current. You may like to check with your care team that this is the most current version available. If not, an updated version can easily be provided.

The resources listed here are those which are generally available across Australia. Space has been allocated for you to record other resources and contact details, particularly those available in your local area. Again, your care team will help you with a specific resource set for your state or territory if one is available.

RESOURCES

The following information is relevant to all families, including those residing in rural and remote areas.



Accommodation support

Your care team will be able to provide information about the options for family accommodation support which will assist you to stay close to your child while attending hospitals and medical checks.

Ronald McDonald House Charities work to improve the health and wellbeing of seriously ill children. Their work includes the Ronald McDonald Houses. Ronald McDonald Houses are attached to major women's or children's hospitals and provide a 'home-away-from-home' for seriously ill children and their families. Access criteria apply.

Ronald McDonald House Charities
PO Box 392
Pennant Hills NSW 1715
T: 02 9875 6666
F: 02 9875 6588
E: rmhc@rmhc.org.au
www.rmhc.org.au

Transport assistance schemes

Angel Flight Australia is a charity that co-ordinates non emergency flights for financially and medically needy people. All flights are free and may involve patients or compassionate carers travelling to or from medical facilities anywhere in Australia.

Angel Flight Australia
T: 1300 726 567 (toll free)
T: 07 3852 3300
F: 07 3852 6646
E: mail@angelflight.org.au
www.angelflight.org.au

Each State and Territory provides travel assistance programs for families who are required to travel long distances while attending to their health care needs.

Ask your care team (specifically your social worker) for information on how best to access these schemes.

A number of charitable organisations have travel assistance programs for families.

Ask your care team (specifically your social worker) for information on how best to approach these organisations.

Financial support

Centrelink provides information on how best to access a range of Australian Government programs for financial support. As a carer, you may be eligible for a number of payments and services.

Centrelink
T: 13 10 21 (for your nearest office)
www.centrelink.gov.au

Information on carers' payments and support
www.centrelink.gov.au/internet/internet.nsf/Individuals/carer_index.htm

Medicare Australia and the Pharmaceutical Benefits Scheme (PBS) provide access to subsidised health care programs for all Australians. Medicare Australia provides access to general practice, specialists, radiology, pathology and optometrists services. The PBS provides access to prescription medicines. Both programs have a Safety Net system to increase the financial benefits as soon as a certain threshold of health expenditure has been reached. Talk with your doctor and pharmacist to be certain you and your family are fully registered and ready to receive these benefits.

When you are entitled to a Health Care Card under Centrelink arrangements, additional subsidies for health costs apply.

Medicare Australia
www.medicare.gov.au

Medicare Public Enquiries Line
T: 132 011 (during business hours)
E: medicare@medicareaustralia.gov.au

Pharmaceutical Benefits Scheme
Enquiries Line
T: 1800 020 613

Location of closest Medicare Australia
Claiming Office or facility
T: 132 011
www.medicareaustralia.gov.au/yourhealth/where_to_find_us/mol.htm






What do the working committees look like?

Clinical Reference Group comprised clinicians and government representatives

- General Practice
- Consultant palliative care paediatrician
- Paediatric palliative care nurses
- Social workers
- Carers Australia
- Commonwealth government
- Palliative Care Australia
- Parent




What do the working committees look like? (2)

Carer Advisory Group comprised

- Parents in focus groups of children with malignant and non-malignant disease
- Parent conversation via in-depth phone interviews

Aim: To ensure the resource meets the needs of the primary target audience, children and their families



What principles need to be considered when different levels of people work together?

- Understanding roles, aims and scope of project
- Understanding how government operates
 - Policy development and implementation
 - Limitations of the project funding
- Health professionals add academic, knowledge of existing resources and experiential content
- Parents add real life experience and insight into what is helpful and not helpful information



Role of parent on Steering Committee

- To add reality and depth to the academic input with the inclusion of both experiences and feelings relevant to the information
- Assist in filtering information
- Ensure the information provided is presented in a clear and concise way that is easily understood by all consumers who may require the resource



Role of parent on Steering Committee

- Provide feedback to and from other parents in carers group who are assessing and reviewing work of the steering committee
- To assist in the development of a format for the resource that is applicable and usable to the spectrum of consumers who will be requiring it



Working with parents and health professionals

- By combining professional knowledge and clinical skills with lived experiences a feasible and multidimensional project is delivered
- Provides a learning experience for clinicians, carers and policy writers



Tailoring each Folder

- Identify basic services in local state
- Identify services in local town or council area
- Identify services specific to child's illness and family's needs
- Add to the folder throughout time

Challenges

- Inclusion of rural/remote
- Inclusion indigenous health professionals
- Interstate collaboration
- Ensuring colleagues reviewing document understood the limitations of the project e.g. aimed at parents not health professionals
- Project officer changes
- Project leadership from a peak body not clinical practice
- Development of a document that meets the needs of families crossing the complexities of remoteness and information technology



Achievements

- Commitment to include families
- Completion of document that has been successfully used across Australia
- User friendly document that is somewhat different to the anticipated product
- Project philosophy and principles can be used in future projects e.g. National Care Planning Project auspiced by The Victorian Paediatric Palliative Care Program



Parent/Carer feedback

Knowledge

- “In a way we have become experts because we have lived the experience not just learnt the knowledge”
- Our biggest regret about this project is that we did not have it when we needed it”

Isolation

- " The thought that there are other families out there going through what we did is gutwrenching, I hope what we have done will help them and let them know they are not alone“

Carers Advisory Group



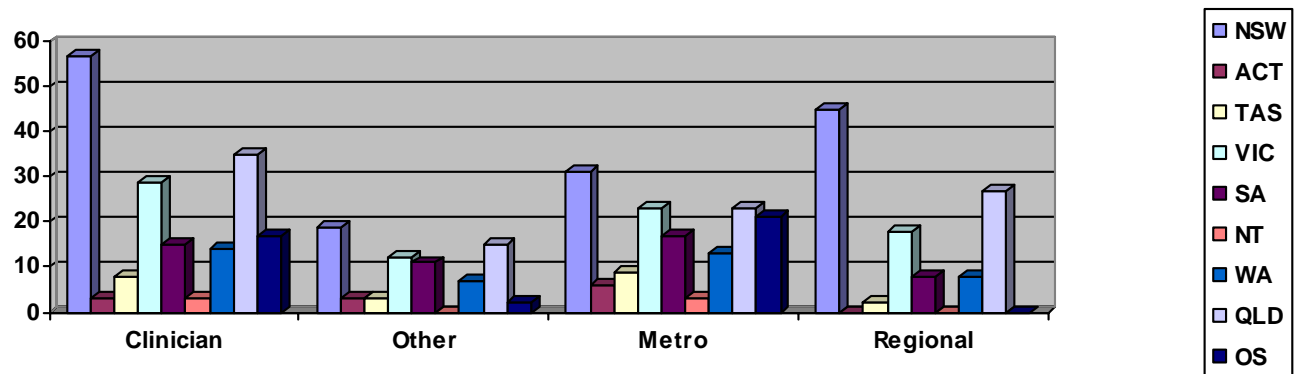
Parent/Carer feedback

Grief

- " I feel as though my daughters struggle and our experiences have not been in vain, to honour her memory by helping other families is such a positive feeling"
- "When died very few people wanted us to talk about it and suddenly with this project we have been encouraged to openly speak and express our experiences and feelings and it has really assisted us in our grieving process"

Carers Advisory Group

Distribution of document



State/Territory	Clinician	Other	Metropolitan	Regional
New South Wales	57	19	31	45
Aust Cap Territory	3	3	6	-
Tasmania	8	3	9	2
Victoria	29	12	23	18
South Australia	15	11	17	8
Northern Territory	3	-	3	-
Western Australia	14	7	13	8
Queensland	35	15	23	27
Overseas	17	2	21	-
Sub Total	181	73	146	108
Total	254			254

Feedback about developing the document

"You often don't know what the questions you need to ask are"

"The language they use can be very difficult to understand, particularly at the beginning when you are not used to it "

"A checklist of what paperwork to do when a child dies eg. Inform equipment suppliers, call doctors, things to cancel – Centrelink, medical insurance"

"But the information has to be localised. I think I'd be frustrated if I didn't have a resource that was localised"

"I was afraid to know at first, I got some amount of information, then did my own research later in my own time. It's common to have fear"

"If caring for someone terminally ill – if the info is hard to get to, you won't bother, you just don't have time"

Preferred Format

- Many want the resource available in both a booklet/folder and a website.
- Women preferred a booklet/folder but felt their husbands would prefer the website
- A booklet/folder is preferred:
 - Not everyone has access to or likes using computers
 - Tangible
 - Can give to parents straight away so that they immediately have something
 - Can pass round to family / friends
 - Its their own personal resource
 - Can carry with them
 - Put on their shelf
 - Convenient
 - Can use it anywhere / pick it up anytime
 - While having a drink, when in bed
 - ↑ Important as they have little spare time
 - Generally prefer a folder including brochures over a book as can copy and/or hand out to family and friends

"A lot of people are computer-illiterate. They could miss out totally"

"If they have a book to give to you from day one and say here, go home and read this it would answer a lot of your questions "

"A booklet's handy - you can read it while doing something else"

"It's personal - it's your own"

References

- Lammers John & Happell Brenda (2004) *“Research involving mental health consumers and carers: a reference group approach”* International Journal of Mental Health Nursing 13, 262-66
- MacPherson, C (2006) *“Healthcare Development Requires Stakeholder Consultation: Palliative Care in the Caribbean”* Cambridge Quaterly Journal of Healthcare Ethics 15, 248-55
- Richardson Alison, Sitzia John, Cotterell Phil (2005) *“‘Working the system’. Achieving change through partnership working: an evaluation of cancer partnership groups”* Health Expectations 8 pp 210-20



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