

What should palliative care in rural Australia look like?

1.

For GPs and Health professionals

1. Easily access services for their patients
2. Ongoing accessible education
3. Resources to support GPs in the referral process
4. GP Management Plans that is easy to use
5. Medicare rebates that are generous for palliative conditions
6. Communication between hospitals and GP Practices
7. A computer system between GP practices and hospitals that supports communication so outcomes are met
8. Communication between oncologists, specialists and GPs

For Patients and Carers

1. Easy access to services
2. Information available at GP practices and hospitals to support patients and carers
3. Pain and symptom relief
4. A plan of treatment
5. Carer support on non-clinical aspects
 - a. eg making a will, support groups, financial support etc
6. Information on clinical aspects that is easy for a non medical person to understand
7. Encouraged to keep a journal or diary to enhance patient responsibility when able
8. A supportive Palliative Care service

2.

- Access to high quality Palliative Care should be available to ALL and should be equal to that available in urban areas
- Palliative care standards should be implemented nationwide to ensure quality overall
- Easy access to medications at all times and at reasonable cost
- Access to ongoing education for all palliative care providers

3.

Seamless Care

- Patient and family centred care
- Patient at centre of care
- Protocols follow the patient
- More allied health staff

4.

More ready access to palliative Care services. At present, patients requiring radiotherapy must travel to Brisbane for treatment. A radium clinic is desperately needed in the local area. The clinic would service all the Central Queensland Area. In Gladstone there is one palliative care nurse practitioner who covers all palliative patients during weekends with one visiting specialist monthly. There are other support services available during the week but the weekend is covered solely by the palliative care nurse practitioner. In Yeppoon there is no coverage for the palliative patients on the weekend – they are usually admitted to hospital for treatment. The implementation of the Electronic Health Record will help alleviate some of the issues but more services and separately needed.

5.

All clients who have need of palliative care services are able to access them:

- Quality end of life
- Choices
- GP managed

6.

- 24hour/7 days a week access to specialist palliative support
- MDTs
- Crisis avoidance

7.

1. Generalist health professionals should be well informed and supported
2. There should be formalised service agreements with Specialist support from metro services
3. Well supported and accessible services irrespective of location eg technology to support access

8.

Well serviced and connected palliative community with ready access to specialist palliative care professionals (not necessarily face to face). Good communication between service providers. Patients are able to make informed choices about end of life care and location.

9.

All services should be talking to each other, ensuring MDT care. The GP or other clinician should be specifically chosen as lead coordinator. All clinicians communicating with all other services about interventions they have initiated. If any clinicians refers the patient to a service provider outside their region, that person is responsible to follow-up and to inform all other clinicians. All clinicians should be aware of service available and be confident in their knowledge of high quality PC.

10.

- GP/Practices being the centre of the palliative care team
- Palliative care/palliative approach being offered to all patients with a life threatening illness when the need arises regardless of the diagnosis
- Sufficient health resources to allow the patient and family to choose site of care
- Availability of specialist palliative care regardless of age, gender, ethnicity and site of care

11.

Planned transport accessible to all

12.

Referral pathway system

- 1 referral made once by the patient, family carer, GP etc
- Referral entered into an effective referral pathway system
- Constant communication networks established – preferred secure electronic
- Phases of care follow as required
- Everyone notified accordingly if symptoms change

13.

- System support for people dying at home
- Integrated service and communication protocols across service between all players

14

- Coordinated
- Planned
- Accessible care

15.

- Regional Governance bodies with representation from multiple sectors eg community, education, business. Government as well as health to consult services and plan strategies that respond to short, medium and long term needs
- Formal connection to SPCS with clear access and discharge guidelines
- Palliative approach embedded in Chronic Disease management

16.

Rural palliative care patients and their families should have access to timely, appropriate and coordinated clinical care and support services to ensure quality in life and dignity in death.

17.

Palliative care should be everyone's business and not solely the domain of specialist teams. Primary health care providers should feel confident in their skills to provide best practices to the patient & families and communities should have the skills and resources to provide support to maintain patients at home.

18.

Access to quality, coordinated, palliative care in rural communities, that is streamlined and focused on patients and their families/carers.

19.

More consultation and integration of services to ensure good collaborative care and more efficient use of funds

20.

Palliative care based on need rather than diagnosis. Same as in metro Australia – equity in service provision and resource availability!

21.

- Timely access to those requiring it and their families provided with appropriate and adequate support
- Adequate service provision eg radiotherapy
 - Radiotherapy use in Australia is 30-35% (internationally 50%)
in the Tweed Valley it is <25%
- Communities have options, home based/ hospital based/ hospice based
- Culturally appropriate

22.

- Access to SPCS
- Education for all health staff
- Access to specific palliative care room in acute and aged care sectors
- 24hour palliative care services to all

23.

- Intentional support mechanisms for health care workers at bedside and coal face of providing end of life care
- SPCS funded to enhance support and provide education to health care workers at the bedside (a true consultancy/palliative approach model)
 - eg Victoria: No mechanism for attributing EFT to education in the data collection for funding. Education and support consultation not supported on a tangible way
- enhanced community engagement and education in regards to the palliative approach
- Intentional grief and bereavement support for isolated rural and remote communities

24.

Equity, Access, Choice, Empowerment

- Access to readily available SPCS for all including 24hour care
- Provision of information related to choice of palliative care environment. Information should include options available locally including, hospital home or RACF
- Immediate access to community services (HACC) to assist home based palliation
- Up-to-date palliative care information for primary palliative care provider and consumers

25.

Flexible to meet the needs of people in differently serviced communities but should be some guiding principles so that there is a standard level of service delivered. It should be formally supported by metropolitan services since there are no other specialist services available in rural communities.

Palliative care should be available to every person in the setting of their choice and there should not be a pressure for it to be delivered in any particular setting.

It should be a coordinated service that is well supported by all involved so that each person gets quality palliative care delivered by appropriate personnel.

26.

A cohesive team with good communication involving all stakeholders! This is so ALL needs are met in a timely appropriate manor.

We need to work together and not in silos to strengthen awareness and encourage a MDT collaborative approach.

27.

Patient and carers should have timely and equitable access to medical, social and emotional support that allows them to live a symptom free life until they die in a place of their choice.

28.

Accessible and supportive options that overcome the limitations of distance and isolation!

29.

"United" "Compassionate" and "Equality" in ALL aspects of End of Life care delivery

30.

The Population Based Approach to Service Development (PCA) would adapt very well to providing palliative care in rural areas