

Establishing a state-wide Paediatric Palliative Care program in WA

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Paediatric Palliative Care

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Western Australia

- Area = 2.5million km²
30% mainland Australia
- Population = 2 million
20% are 0-14yrs
75% live in greater Perth area



Palliative Care at PMH



- Oncology Department began palliative care for oncology patients ~10 years ago following a service review:
 - Implemented a Oncology Total Care Unit model with a case management approach
 - Palliative care part of this model

Palliative Care at PMH



- With the Oncology TCU palliative care model the lack of services for non-oncology patients became obvious
 - No focus on PPC needs for non-oncology children
 - Medical model/hospital-based care
 - Few choices offered to families
 - Ad hoc planning

Palliative Care at PMH



“Paediatric Palliative & Supportive Care: the needs of children and families in WA” (2004/2005)

- Identified child/family needs:
 - to be at home
 - to be supported by PMH
 - to have information/education
 - to have access to respite
 - to have support for community-based health professionals

Palliative Care at PMH



- **WA Cancer & Palliative Care Network**
 - Federal funding to support PPC model
 - Project Worker (part time)
- **PMH Foundation funding**
 - CNC (full time)
 - Medical Consultant (1 session/week)
 - Continue current Oncology PPC service
 - New focus on non-oncology population
 - State-wide service

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Aims for non-oncology PPC

- PPC CNC to focus on this group of children
- Aim to bring their care to the level offered to the oncology PPC group
 - once achieved, consider merging of some PPC services



Non-cancer diagnoses



- **Perinatal**
 - congenital anomalies
 - complications of prematurity
 - birth asphyxia/HIE
- **Neurological**
 - neurodegenerative (Batten disease)
 - neuromuscular (muscular dystrophies, spinal muscular atrophy)
 - Cerebral Palsy, HIE
- **Organ failure**
 - liver, heart, renal
- **Progressive metabolic disorders**
 - Hurler's, Niemann-Pick, Krabbe, Tay-Sachs
- **Chromosomal abnormalities**
 - trisomy 13, trisomy 18
- **Congenital anomalies**
 - cardiac, spina bifida, CNS, gastrointestinal, pulmonary
- **Respiratory**
 - CF, BPD
- **Infections**
 - HIV, TB

Key issues for non-oncology PPC population



- Uncertain illness trajectory
- Often progressive conditions
- Complex co-morbidities
- Rare/Unknown disorders
- Genetic implications (e.g. siblings affected)
- Increasing complexity of medical interventions
- Parental workload and ongoing stress
- Multiple teams and services involved

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Variable trajectories in non-oncology conditions



- May have periods of good health or plateau at a stable state
- May have many near-death episodes then stabilise
- May have slow deterioration with acute final stage

This variability leads to uncertainty and potential reluctance to refer to PPC services

PMH PPC Referral Criteria



Life-limiting Illness (LLI) /
non-curative condition

AND/OR

DNR order in place

AND/OR

Possibility of death in next 12 months

OPEN REFERRAL SYSTEM

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PPC aims

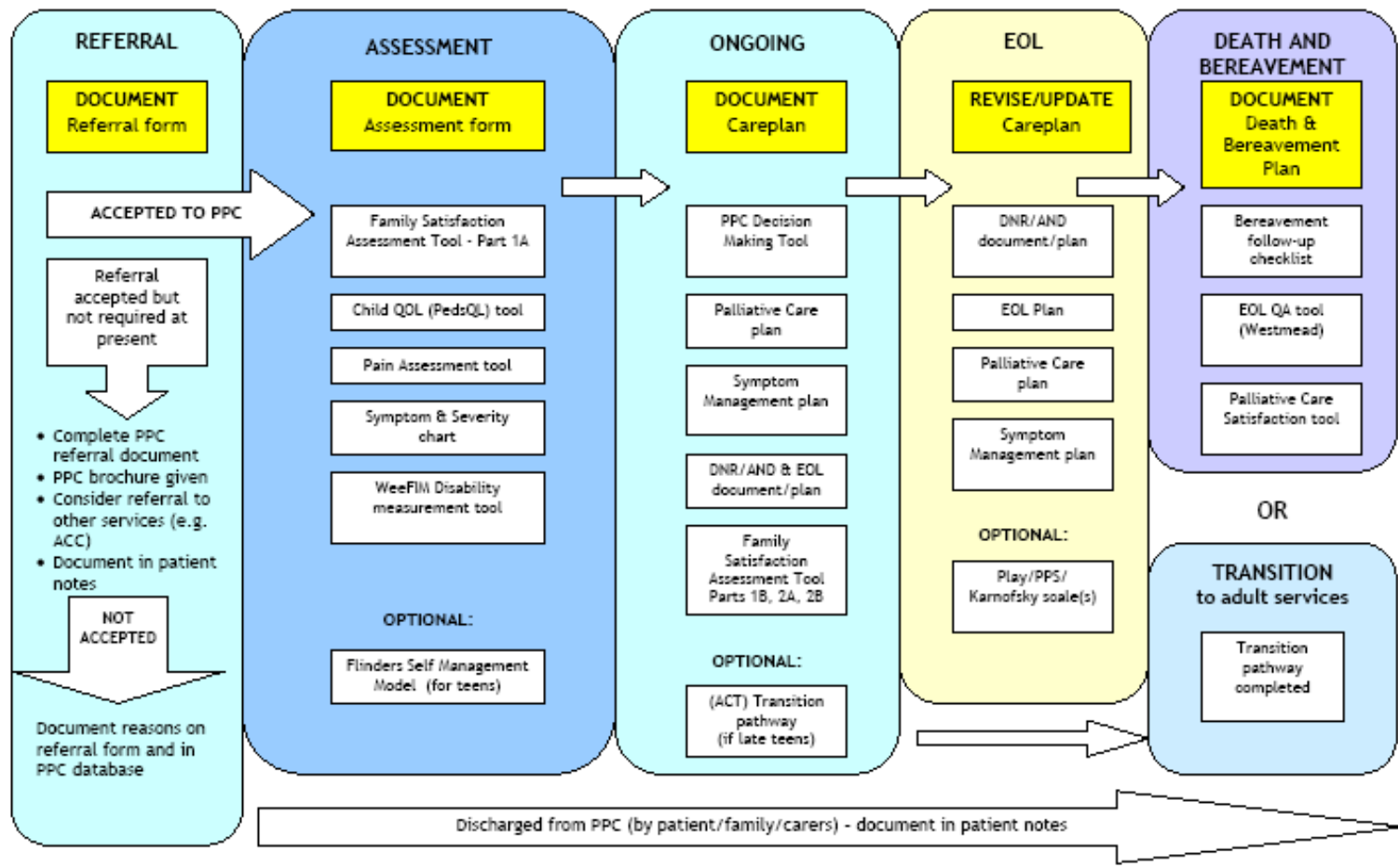


- Provide comfort and symptom management
- Facilitate decision making
- Help coordinate care and improve communication
- Family-centred care in truest sense: child, sibling, family care
- Provide practical help with equipment, medications, respite
- Ensure families have support during bereavement

Hope for the best, prepare for the worst



Screening Tools & Documentation for PMH PPC program



Quality Assurance tools



- Child & Family QOL tool (PEDS QL)
- Family PPC Satisfaction Tool
- weeFIM (physical ability)
- Symptom assessment
- EOL survey & Satisfaction with PPC survey
 - Staff
 - Family

Sources for PPC tools



Microsoft PowerPoint - [CHA DOWDEN Nov08.ppt]

Home - Promoting Excellence - Microsoft Internet Explorer provided by Department of Health

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Promoting Excellence in End-of-Life Care

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- Tools
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Innovative Models and Approaches for Palliative Care

Promoting Excellence in End-of-Life Care was dedicated to long-term changes to improve health care for dying people and their families. Through the work of innovative demonstration projects and national workgroups we strived to address particular challenges to existing models of hospice and palliative care.



Promoting Excellence Tools

Clinical Care Tools Advance Care Planning, Clinical Assessment, Bereavement, Pain Management, Psychosocial...	Evaluation Tools Clinical Quality, Community Assessment, Cost Utilization, Education, Organizational, Programmatic...
Educational Tools Clinician Education, Community Education, Patient/Family Education...	Organizational Tools Enrollment Criteria, Informed Consent, Organizational Assessment...

[Key Clinical Assessment and Research Tools](#)
A collection of published and validated palliative care tools

[Grantees \(Demonstration Projects\)](#)
Innovative projects of national significance in the field of palliative care

[Resources](#)
Articles, Audio/Visual, Books, Chapters, Reports...

Special Initiatives
[NHPCO Conference Learning Tracks](#)
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Target audience for PromotingExcellence.org:

Internet Show when inserting new slides

Care plans



- PPC care plans
- DNR/AND documentation
- Symptom management plans
- End-of-life plans

Increased staff satisfaction:

“We knew what to do as there was clear documentation”

The first 4 months - statistics

First 4 months:

- 18 referrals
- 2 families with siblings affected
- 17/18 are non-verbal (incl 3 infants) with significant medical comorbidities and/or disabilities
- 3 terminal at referral
- 3 with 'pending' PPC needs
- 4 deaths



The first 4 months - diagnoses



- Neurological
 - neurodegenerative, neuromuscular, CP, HIE
- Chromosomal abnormality
- Cardiac
- Perinatal

Key PPC issues so far



- Communication issues around medical treatment options
- Medical complexity of patients
 - co-morbidities
 - high level of medical technology
- Need for excellent interagency cooperation
- Child Protection involvement with 30% of referrals
- Complex ethical issues
- Low level of understanding of PPC
- Need for education: PMH, agencies, general community

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Key PPC issues so far



- Communication around treatment options
 - Has the medical team explained the situation?
 - Has the family 'heard' what was said?
 - Is the treatment helpful, burdensome or futile?
 - Have *all* options been explored?
 - Is there a plan for care?
 - Is there a DNR/AND document?

A parent's words



" Our palliative care nurse had discussed in depth with me the journey we were now going to embark on with M, what we wanted her to experience and what we could expect in the coming weeks.

This was all about M and her body: regaining control of her life and making the precious time we had left as comfortable and pleasurable for her as possible and for us it was about making memories. "



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