

Chronic illness in Palliative Care

Survey of Staff at Peninsula Home Hospice 2016

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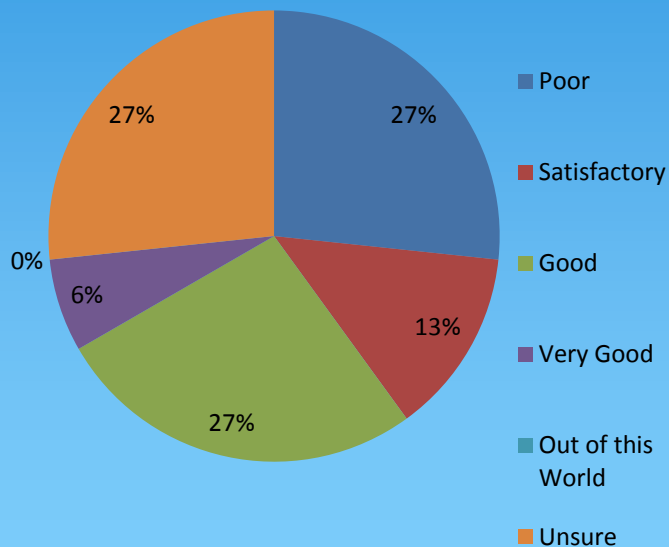
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Introduction

New Portfolio on Chronic Illness August 2015

- * *What are the staff and client needs?*
- * *What are the staff skills and strengths?*
- * *How can we develop our programs further to impact comprehensive service provision in community?*
- * *Exploration of new research*
- * *Exploration of innovative and relevant new programs and services*
- * *Detailed Staff survey in 2016*

Clinicians perception of clients experiencing transitioning to palliative care



- ✓ Lack of current knowledge re Palliative care services
- ✓ Sense of abandonment or rejection by other long-term clinicians/programs
- ✓ Client/carer adjustment to chronicity of illness – often unprepared for next final stage
- ✓ Shock re finite prognosis
- ✓ Clients unable to discuss palliative care
- ✓ Variables impacting the transition:
 - ✓ **Role of clinicians to demystify palliative care**
 - ✓ **Every situation is different**
 - ✓ **Clinicians own understanding and comfort of talking about specialist palliative care and life-limiting illness**
 - ✓ **Referrals from after hours staff**
 - ✓ **Better outcomes with earlier referrals**

Benefits:

What benefits do you think the client experiences as a result of being on PHH community palliative care program?

* Trust: as relationships build

- * Care at home
- * Opportunity for future planning
- * Emotional support
- * Opportunity to prepare for death/transparent conversations
- * Honest/transparent conversations re treatment options -> Informed/supported
- * Assist maintain independence
- * Assist grief/bereavement
- * Financial assistance



- * A comprehensive support system:
 - * Home based rather than clinic based
 - * Support for carer/family
 - * holistic focus - overview of the sum of body parts – not just one part or specialty
 - * Symptom management -> reduce hospital admissions
- * After hour support/phone number
- * Access -> resources
- * Quality team approach/multiple services

Strategies: *What skills/strategies do you bring to the client when working with chronic illness?*

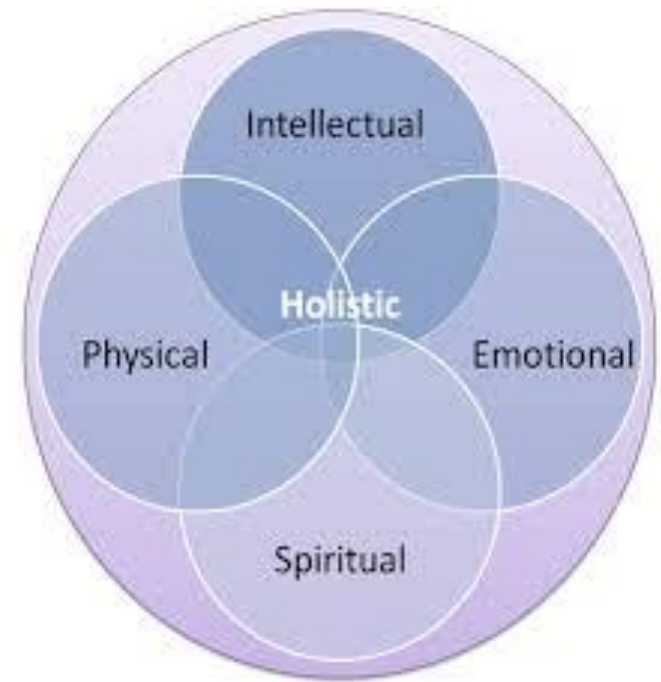
- * Knowledge:
 - * Resources
 - * Illness and Trajectory
 - * Clarity re services
- * Experience:
 - * Conversations and education re death and dying process
 - * Empathy/finding personal and individual meaning
- * Skills:
 - * Having the difficult conversations
 - * Communication and active listening
 - * Normalisation and respect of feeling
 - * Advocacy
 - * Symptom management
 - * Assessment
 - * Family And Carer Assessments



- * Person Centred Approach:
 - * Respect for clients knowledge
 - * Respect for carers role
 - * Responsive to client need

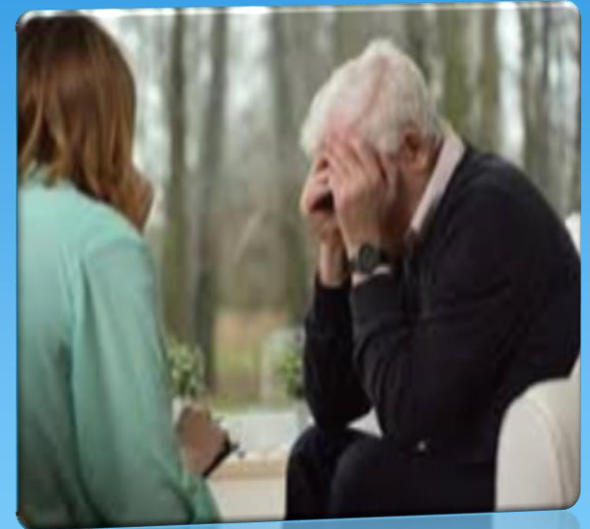
Strategies: *What skills/strategies do you bring to the client when working with chronic illness?*

- * Holistic alternative strategies/solutions
 - * Coordination of all physical symptoms → not limited to one part of the body/speciality area
- * Clinical
 - * Symptom management
 - * Medication management
 - * Liaising with specialist/GP/services
 - * Counselling, Family Therapy, Case Management
 - * Bereavement counselling
 - * Art and Music therapy
 - * Spiritual Care
- * Education re palliative care vs terminal care
- * Staff awareness re carer burnout/self care



Depression: high prevalence in chronic illness – please comment on how this has affected your experience with clients who have chronic illness.....

- ❑ Differentiation – depression/situation reactive sadness
- ❑ linked anxiety (contagious to family)
- ❑ Complexity – limited beneficial response to meds and other strategies
- ❑ Depression - Chronic Illness paralleling physical illness
- ❑ Linked to emotional exhaustion for carer/family/friends
- ❑ -> Isolating
- ❑ How to initiate and maintain hope
- ❑ Fear of going into care if burden too high



“In some clients a defeated state of sensing that nothing is able to change or improve their state. High fatigue or flatness challenging the interest or availability to engage with supports”

Symptom Issues:

Do you find a particular symptom, or combination of symptoms more challenging in your work with clients with chronic illness



- * Dyspnoea - difficult to manage in some clients
 - * Associated anxiety/psychological fear
- * Incontinence and dementia – increase in carer workload/embarrassment for client and carer
- * Lower leg oedema
- * Dysphasia
- * Physical deterioration -> brain and cognitive ability good
- * Fatigue – difficult coming to terms
 - * challenging the interest or availability to engage with supports
- * Carer Strain
- * Language and communication - particularly with MND
- * Pain and nausea

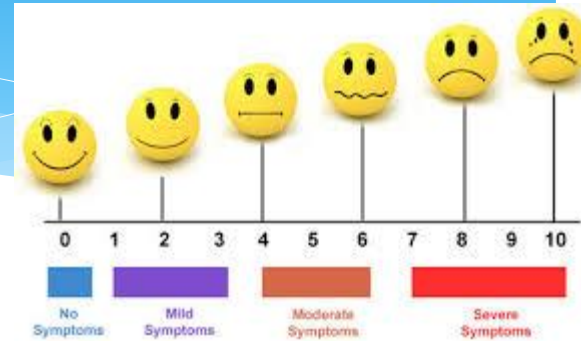
Challenges: *What are the challenges you face with communication at assessment if the clients' illness has affected communication/cognition?*

- * Reliant on carer's perspective
- * Checking understanding and overall communication
- * More time needed for assessments (which may happen over several visits)
- * Getting a clear picture (without assumptions)
- * Client's informed consent
- * Clients who live alone
- * Lowered capacity for focus/concentration, and behavioural issues
- * Clients not remembering strategies
- * Greater need for HCP continuity in service provision



Communication/cognition: *What tools and skills are used successfully to help you ascertain symptom levels when communication/cognition is limited?*

- * Recognising visual cues - facial expressions and body language
- * Faces pain scale
- * Liaison with nurses/other health care professionals
- * Attentive listening to primary carer
- * Communication devices
- * Observing interaction between client and carer or family
- * Repetition
- * Research and history collection
- * Written strategies
- * Flexibility and creativity
- * Person centred care
- * Relationship building through consistent supportive care
- * Carer and family feedback



Client age: *Does the age of the client with the chronic illness affect you personally? Please state why*

- * No 46%
- * Yes 46%
- * Variables impacting include length of illness, age of diagnosis, and quality of life
- * Staff challenged by clients in similar life stage to their own
- * Young clients including children more challenging, seen as “unfair”
- * Staff strongly disagree that older people would be more accepting
- * Staff witnessing clients “fed up” or “had enough” strong motivators for acceptance of Palliative Stage
- * “No illness is part birth, living and dying. It is common to all of us”



Carer & Family: *What do you feel is most helpful for carer/family from a palliative care program, when they have been living with a chronically ill family member?*

- * Clear consistent support and communication
- * respect the systems in place
- * Respite options
- * Symptom management and expertise
- * Practical/case management support
- * Emotional support -> counselling, MT and AT
- * To be available -> conversations re dying/death/bereavement
- * Building trusting relationships-> continuity
- * 24/7 nursing support
- * Coordination of care
- * Communication between chronic illness clinics/specialists and PHH

Personal challenges: *What can be uniquely challenging in your role when working with the family of the chronically ill person?*

- * Financial burden
- * Preventing burn out/poor morale
- * palliative needs vs chronic illness needs
- * Equipment in the home – access to music players or apps/programs
- * Appropriate support/referrals - ongoing assistance eg children connected to school support programs
- * Continuity of care
- * complexities
 - * family/dynamics
 - * mental health issues
 - * relationship issues
 - * long standing family issues
- * cumulative stress/exhaustion
- * ‘sitting with’ carers -> transition to palliative
- * Future planning -> urgency in providing support

They're “over it and often sick of health professionals”

Future services:

Is there a program, service, or aspect of palliative care that would be helpful to these carer/families not currently happening at PHH?

- * Exercise programs
- * Breathing clinic
- * Day respite
- * Group music program -> transition for carers in bereavement
- * Team approach -> to support the carers/family
- * Group programs for Clients only and Carer's only
- * Increased support -> considering complexities of the client/carer

“Asking clients/families what they would like to receive from us... give us a clue to another program or service we could initiate...”

Where to from Here?

- * Strengthening relationships with referral source –to improve transition
- * Further staff education on dementia
- * Reinforcing pathways for dealing with challenging symptoms in community
- * Clinical review - Depression and palliative care
- * More conversations around the needs of chronically ill clients and their families at MDT, case conferences and organisational planning

Portfolio

- * Further research and exploration of needs/issues/strategies specific to this client group
- * Continued strengthening of partnerships with chronic illness/symptom clinics in local area
- * Continued support of staff