idea services

Living Every Moment hospice waikato

DISABILITY SECTOR

PALLIATIVE CARE PATHWAYS

Contents

Acknowledgements

These pathways are the result of a collaboration between IDEA Services, Hospice Waikato, ConneXu and Health New Zealand Waikato DSS.

Purpose

This document marks a collaboration between stakeholder services who support the optimisation of dignified dying for people in the disability sector, in particular the intellectual disability sector. The organisations involved in this project believe that by working together we can improve care and quality of life in the palliative and end of life stages for clients. There are opportunities to be more coordinated, more aligned, and more proactive which will assist disability consumers to have better coordinated care and quality of life in their palliative journey.

People with intellectual disability who receive support from a community support provider are the focus group for this project, hereafter referred to as clients.

This pathway approach could be transferred across many settings.

Aim

Clients who have intellectual disability are provided with well-coordinated, responsive and collaborative care, delivered by trained, supportive and knowledgeable staff who will support them to live well and die well in their palliative and end of life journey.

Principles

1. The client receives the right care at the right time by the right person/s, equitably, regardless of where they live.
2. The collaborative pathway will be led by the disability provider and services will work to be interdisciplinary, interagency and will collaborate to coordinate care.
3. A collaborative plan of care will be presented to the client for consent. If support towards consent is required, the disability provider will facilitate this. The plan will include a list of services/people involved.
4. Proactive advance care planning is advantageous and should be in place to support the client's transition from living well to dying well, including support for whānau and staff as needed.
5. Wherever possible, the client will be enabled to retain control and appropriate decision making through honest conversations, and all attempts will be explored to minimise pain and distress (physical, emotional, social, spiritual).
6. Agencies involved will show interagency respect and understanding of other agencies' time constraints and capabilities. They will contribute to coaching, mentoring, debriefing and case reviewing, support, education and access to resources as agreed.

We acknowledge the constraints within the sectors involved and the principles and considerations above are a reminder to discuss, agree and collectively plan for and commit to the best outcome possible.

Preparation Recommendation Checklist for Disability Provider

Yes/ No	Prompt	Comment
	Clarify who is leading/ coordinating (named staff within provider organisations, who must be accessible and back up person).	
	Advanced Care Plan available to reference client's wishes and goals or working towards with client, whānau and GP.	
	Home environment, space, suitability for future equipment that may be required. Know how to access necessary equipment.	
	If the client may need to move to a different home within the service, start planning early.	
	Skills and education for staff, including if there are new physical needs related to palliative care, such as increased personal care needs, manual handling or pressure area care. This may be internal programmes or outreach, e.g. hospice or district nursing.	
	Skills and education for staff for palliative care, including recognising dying. This may be internal programmes or outreach, e.g. hospice carer training and related resources.	
	Psychological safety for support team. This may be internal programmes or outreach, e.g. hospice or EAP.	

Yes/ No	Prompt	Comment
	Cultural considerations of client and support team.	
	Expectations of family/whānau – clear communication plan is agreed.	
	Planned palliative care vs. reactive end-of-life care, e.g. planning for demographic, ageing earlier, increased demand.	
	Needs assessment/funding change, including potential overnight awake support need. Consider options if client may not be able to stay within service.	
	Impact of others in the home or nearby flatmates.	
	Registered with a GP, preferable existing relationship, knows client well.	

1. Increasing frailty and normal dying

Proactive plan

Actions for provider

Increasing frailty and normal dying does not usually require input from specialist palliative care services such as hospice.

This might be different if a client has complicated conditions such as fragile epilepsy or mental health and regular medication needs, or symptoms of suffering, and they are no longer able to take medications orally.

- Follow up with GP based on observed changes/new symptoms and request referrals required.
- Complete the Preparation Recommendation Checklist (see pages 4/5).
- Contact internal clinical support if available.
- Consider level of frailty using assessment tools (see Appendices).
- Seek supportive assessments with allied health professionals as needed such as:
    - ◊ speech language therapist – for swallowing changes
    - ◊ dietitian – to maintain optimum nutrition
    - ◊ physiotherapist – for safe mobility assessment and plan
    - ◊ occupational therapist – for supportive equipment assessment or review
    - ◊ continence nurse – to optimise products
    - ◊ geriatrician – for supportive diagnostics
    - ◊ clinical pharmacist – to review medications
- Consider if additional learning to what is suggested in the Preparation Recommendation Checklist may be of benefit, e.g. understanding dementia or pressure area care.
- Consider welfare guardianship as needed or enacting enduring power of attorney (EPOA).

2. New life-limiting diagnosis
Proactive plan

Actions for provider

A new diagnosis of a life-limiting condition or disease may trigger engagement with specialist palliative care services such as hospice.

At times, the diagnosis is made when the disease is already advanced for several disability related reasons. So, early engagement with specialist support is ideal to build relationships and collaborate for the best possible experiences for everyone involved.

- Follow up with GP based on observed changes/new symptoms and request referrals required.
- Complete the Preparation Recommendation Checklist (see pages 4/5).
- Contact internal clinical support if available.
- Inform funder of change in circumstance/new diagnosis.
- Consider level of frailty using assessment tools (see Appendices).
- Advanced care planning and goals of care discussions and documentation is vital.
- Seek supportive assessments with allied health professionals as needed such as:
    - ◊ speech language therapist – for swallowing changes
    - ◊ dietitian – to maintain optimum nutrition
    - ◊ physiotherapist – for safe mobility assessment and plan
    - ◊ occupational therapist – for supportive equipment assessment or review
    - ◊ continence nurse – to optimise products if needed
    - ◊ geriatrician or other specialist related to diagnosis – for supportive diagnostics and management pathways
    - ◊ clinical pharmacist – to review medications
- Consider if additional learning to what is suggested in the Preparation Recommendation Checklist may be of benefit, e.g. understanding dementia, congestive heart disease or cancer.
- Consider welfare guardianship as needed or enacting enduring power of attorney (EPOA).

3. Sudden/unexpected change in support needs

Reactive plan, related to education and advanced care planning

Actions for provider

A sudden change in support needs, related to a life limiting diagnosis, may trigger engagement with Specialist Palliative Care services such as Hospice.

Life limiting diagnosis may present with periods of more sever illness and plateaus, but each time the person has an episode of illness, they may not "bounce back" as well.

Careful discharge planning from a hospital admission is vital. Use the Preparation recommendation checklist and organisational internal resources to plan and facilitate a safe and appropriate discharge.

- Referrals to specialist supports and allied health should be factored into a safe discharge from hospital.
- Follow-up GP based on observed changes/new symptoms and request referrals required and after a hospital admission so they are aware of the changes.
- Contact internal clinical support if available.
- Inform funder of change in circumstance/new or worsening diagnosis.
- Consider safe staffing levels at available notice.
- Implementation of supplementary roster, e.g. night awake cover if needed.
- Consider level of frailty using assessment tools (see Appendices).
- Advanced care planning and goals of care discussions and documentation is vital.
- Ensure any organisational care plans are reviewed and updated.
- Seek supportive assessments with allied health professionals as needed such as:
    - ◊ speech language therapist – for swallowing changes
    - ◊ dietitian – to maintain optimum nutrition
    - ◊ physiotherapist – for safe mobility assessment and plan
    - ◊ occupational therapist – for supportive equipment assessment or review
    - ◊ continence nurse – to optimise products if needed
    - ◊ attend outpatient specialist follow up appointments as necessary to assist with care pathway planning
    - ◊ clinical pharmacist – to review medications
- Consider if additional learning to what is suggested in the preparation checklist may be of benefit.
- Consider welfare guardianship as needed or enacting enduring power of attorney (EPOA).

4. End-of-life intensive support

Reactive plan with proactive elements, related to education, communication and advanced care planning

Actions for provider

An end-of-life intensive support pathway will include specialist palliative care services such as hospice and or district nursing.

This pathway is actioned when it is not expected that the client will "bounce back" and they require specialist input to manage their symptoms or needs.

If the client has been in hospital prior, careful discharge planning is vital. Use the Preparation Recommendation Checklist and organisational internal resources to plan and facilitate a safe and appropriate discharge.

- Referrals to specialist supports and allied health should be actioned by the hospital medical team, or GP as soon as person is home or has been assessed by GP.
- Contact internal clinical support if available.
- Follow up GP/hospice team based on observed changes/new symptoms so they are aware of the changes as they occur.
- Inform funder of change in circumstance/new or worsening diagnosis
- Consider safe staffing levels at available notice.
- Implementation of supplementary roster, e.g. night awake cover if needed.
- Consider level of frailty using assessment tools (see Appendices).
- Advanced care planning and goals of care discussions and documentation is vital.
- Ensure any organisational care plans are reviewed and updated.
- Seek supportive assessments with allied health professionals as needed such as:
    - ◊ speech language therapist or hospice guidance – for swallowing changes
    - ◊ physiotherapist – for safe mobility assessment and plan as needed
    - ◊ occupational therapist (or hospice) – for supportive equipment assessment or review
    - ◊ continence nurse – to optimise products if needed
    - ◊ GP or hospice team – to review medications
- Consider if additional learning to what is suggested in the Preparation Recommendation Checklist may be of benefit.
- Consider enacting enduring power of attorney (EPOA) as appropriate.
- Ensure cultural safety of support team.
- Review end-of-life care documentation for ceilings of care and resuscitation status with everyone so support network knows what to expect.

Implementation Recommendations for Other Stakeholders

Disability Funder

- Reassessment of support package.
- Support referrals to allied health services as needed.
- Engage social worker or Te Whatu Ora disability liaison personnel if client is in hospital. If not in hospital, the funder link would be the coordinator.
- Ensure care navigation is in place, and prompt provider to implement if needed.

Primary Care

- Assess symptoms of concern. If this is difficult, suggested disability specific tools are available in the Appendices.
- Review/rationalise medications.
- Refer to allied health for necessary assessment.
- Advanced care planning support if available, e.g. support for ceilings of care and medical decision making. This could be built into annual health check allocated appointments if appropriate.
- Consider disease trajectory and early engagement with specialist palliative care if it is possible that symptoms may be difficult to manage within six months.

Specialist Palliative Care

- Referral received and accepted.
- Meet client and support network.
- Potential for education as negotiated.
- Coaching for staff as agreed.
- May include, for example, education about frailty assessment, symptom assessment and management and what to expect in the coming months.
- Clinical nurse specialist assessment to implement joint palliative approach.
- Consider aetiology, practical palliative cares, e.g. mouth cares, pain recognition and management, sub-cut medications if provider policy allows alternative routes such as nasal direction/delegation.
- Psychosocial health, family/whānau support needs.
- GP liaison as appropriate.
- Bereavement support.

Other

- Hospital admissions
- Hospital discharge coordinator for complex patients, social worker or Te Whatu Ora disability liaison personnel to support and enhance communication and safe discharge planning with disability provider.
- Referrals to outpatient clinics or specialists, or district nursing or hospice services if needed.
- Support to apply for PPPR if person is in hospital and has no legal representation if needed.

Appendices of Useful Tools and Links

Hospice New Zealand website

www.hospice.org.nz

Hospice New Zealand Guide for Carers booklet

www.hospice.org.nz/hospice_guide_for_carers

Te Ara Whakapiri: Principles and guidance for the last days of life

www.tewhatuora.govt.nz/publications/te-ara-whakapiri-principles-and-guidance-for-the-last-days-of-life/

Abbey Pain Scale

www.mercyhospice.org.nz/wp-content/uploads/04_32-36-Pain.pdf

Disability Distress Assessment Tool (DisDAT)

This tool helps observe and identify distress cues in people who have severely limited communication because of cognitive impairment. Its use is based on the person's usual content cues and helps staff to feel confident in using their observation skills.

www.betterlives.org.uk/wp-content/uploads/2014/01/disdat_form.pdf

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