NAVIGATING END-OF-LIFE CARE

Li-Ve TASMANIA | HEALTHY DYING FOR PEOPLE WITH DISABILITY

This navigation tool is designed to guide disability support staff in their care of people living with disability who have a life-limiting illness. This tool is to be used in conjunction with medical input.

Person with disability health and wellbeing has changed

Arrange a visit to the GP. Disability support worker to provide GP with all the relevant information using ISOBAR form

Y

Communicate/liaise with the GP or medical specialist about ongoing clinical care

Y Life limiting illness confirmed?

Y

Medical Goals of Care completed by GP/ Medical Specialist. This plan records the person goals and wishes for end of life. All team members need to be made aware of the plan

Support Coordinator initiates Care Plan review based on the person's end of life goals

The person, their family, carers are provided with clear information about the illness and death and dying

The GP or Medical Specialist determines the most appropriate clinical pathway including clinical care needs

Choose one pathway

Person with disability is diagnosed with life limiting illness	Diagnosis of a life limiting illness	Follow this pathway
Person with disability health and wellbeing is declining (which may be slow or quite rapid) needing increased support	Declining health and wellbeing	Follow this pathway
Person with disability is nearing the end of their life and requires assistance related to palliative care	End of Life	Follow this pathway
Person with disability needs full assistance to die	A Good Death	Follow this pathway

CARE CONTINUUM

Note: Documenting in a person's file and progress notes is important for continuity of care

TEAM MEETINGS/CASE CONFERENCING

The goal of case conferencing is to

- provide person centred coordinated care at end of life
- Provide a team and skills based approach to care
- Review progress and barriers towards goals

COMMUNICATION

- Communicating with the person with disability about death and dying in a way that is easy for them to access and understand is important. It may take time.
- It is important to know if the person with a disability has a substitute decision maker/guardian and they are involved in end-of-life care planning
- Good communication involving all health care team members including disability support workers is essential for end-of-life care

Practice Point

- Each person is an individual. They will experience a life limiting illness differently.
- Closely monitoring and responding to changes in a person's health and wellbeing is important

Diagnosis of a life-limiting illness

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Diagnosis of a life limiting illness | Declining Health and Wellbeing | End of life | A good death

Introduce the palliative approach.

A palliative care approach
- Encourages open discussion and planning about death and dying
- Provides improved symptom control such as pain
- Involves the people that matter most to the person dying
- Involves staff who are known to the person
- Minimises the risk of a crisis
- Promotes healthy living until death

Y → **Is a clinical assessment needed?**

Y → **Is referral required?**
- General Practitioner
- Specialist Palliative Care Service
- Community nursing
- Positive behaviour specialist
- Occupational Therapist
- Dietitian
- Social worker

Y → **The most appropriate person to arrange referral**

Everyone needs to know the plan to support end of life goals

Communicate findings

Explain treatment and follow-up Care Plan to the person and carer.

Document outcomes in persons progress notes and update Care Plan.

Share Care Plan with the person, carer, and GP. Ensure plan is accessible by all team members.

Consider arranging a case conference with the health care team to confirm the goals of care and ongoing coordination of care arrangements

REVIEW TIMEFRAME:

Report when a change occurs to support coordinator

N → Continue to promote independence and monitor the persons health and wellbeing. Report any changes using STOP AND WACTH

Y → REVIEW TIMEFRAME

N → REVIEW TIMEFRAME

Person with disability, family or substitute decision maker may need information about
- Advanced care directive – this is helpful to have in place early to guide

Note: All care provided to be documented using progress notes.

Practice Point
- Each person is an individual. They will experience a life limiting illness differently.
- Closely monitoring and responding to changes in a person's health and wellbeing is important

CARER SUPPORT
- Carer(s) and family need to be involved in the persons care plan and delivery.
- The Carer has their own care pathway.
- Respite, counselling, training and education can be extremely helpful.
- Carer Gateway has resources and services available to support carers.

COMMUNICATION
The most appropriate person is to:
- communicate with the health care team about the persons clinical care needs
- communicate with the **persons disability support workers** about any changes in the Care Plan
- assist the **person** to navigate the health care system to access the health care and support they need.

MEDICATION MANAGEMENT
- It is important to follow organisational policy which needs to reflect Tasmanian law
- Only disability support workers who have received medication management training may administer medications dispensed by a pharmacist
- DSWs must not administer medication via a standard syringe, including injection of medication into intravenous lines or use of similar equipment that is sited intravenously.
- DSWs should not administer medication that requires clinical assessment or clinical judgment.

Declining health and wellbeing

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Diagnosis of a life limiting illness | **Declining health and wellbeing** | End of life | A good death

Is a clinical assessment needed? Y → **Clinical assessment**

Consider if the person has difficulties with
- Nausea
- Pain
- Anxiety or distress
- Skin integrity
- Cognitive decline
- Behaviours of concern
- Mobility or falls
- Managing their continence
- Meeting their spiritual, cultural or social needs

N → **Disability Support Worker's** to use the STOP AND WATCH instrument to report and respond to any changes.

Is referral required? Y → **Arrange referral**

Consider
- General Practitioner
- Medical specialist
- Specialist Palliative Care Service
- Community nursing
- Positive Behaviour specialist
- Occupational Therapist
- Dietitian
- Social worker
- Pharmacist

N →

The most appropriate person to communicate with the team

Communicate findings

Explain treatment and follow-up Care Plan to **the persons with disability and carer**.

Document outcome of referral in client notes and update Care Plan.

Share Care Plan with the person, family and **GP**. Ensure Care Plan is accessible by all **team members**.

If appropriate, **Clinical Case Manager** in collaboration with **GP** may introduce concept of a palliative approach.

Arrange a conference with the health care team to confirm the goals of care and ongoing coordination of care arrangements

REVIEW TIMEFRAME: When a change occurs

Emergency or after-hours services

- Ambulance Tasmania – Emergency and Extended Care Paramedics
- Health Direct – 1800 022 222
- Call the Doctor – 1800 225 584

Person with disability, family or substitute decision maker or guardian may need information about
- Advance Care Directive – this is helpful to have in place early to guide ongoing care

Note: All care provided to be documented using progress notes

TRANSITIONS OF CARE

- When communicating with health care providers use the following process
- I – **Introduce** yourself and the person
- S – describe the **situation**
- O – describe your **observations**
- B – provide the **background**
- A – describe your **assessment**
- R – provide your **recommendations**

COMMUNICATION

Team members need to:
- regularly monitor the client's health and wellbeing.
- communicate with the Disability Support Worker about any changes in the Care Plan
- communicate with **Clinical Case Manager** about clinical care
- facilitate and participate in case conferencing with **all team members.**

The most appropriate person is to:
- liaise with **GP** and all **clinical team** members
- promote continuity of clinical care across health care settings
- participate in case conferencing with **all team members**.

MEDICATION MANAGEMENT

Monitor the effectiveness of medications used for symptom control

Refer to GP or Specialist Palliative Care Services if symptoms are not well controlled

End of life

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Diagnosis of life limiting illness | Declining health and wellbeing | **End of life** | A good death

Is a clinical assessment needed? Y → **Clinical Assessment**

Consider if the person is having difficulty with
- pain
- nausea
- anxiety or distress
- skin integrity
- behaviours of concern
- bleeding
- breathlessness
- oral hygiene
- restlessness

N → Disability Support Workers review the persons health and wellbeing needs regularly. REPORT any changes using the STOP AND WATCH instrument

Clinical Assessment → Y → **Is referral required?**

- General Partitioner
- Specialist Palliative Care Service
- Community nursing
- Positive Behaviour Support provider
- Pharmacist
- Occupational therapist

N → **REVIEW TIMEFRAME:** Report any changes to support coordinator

Is referral required? Y → **Arrange referral** → **Communicate findings**

The most appropriate person

Explain treatment and follow-up Care Plan to the person and carer.

Document outcome of referral in progress notes and update Care Plan.

Share Care Plan with the person and carer, and GP. Ensure Plan is accessible by all team members.

Follow up and **liaise** with the health care team including disability support workers ensuring a palliative approach → **REVIEW TIMEFRAME:** Report any changes to support coordinator

- Everyone involved in a person's care is part of their health care team and play an equal role
- Supporting people with disability access safe high quality health care is everyone's responsibility

Emergency
- Ambulance Tasmania – Emergency and Extended Care Paramedics
- Health Direct – 1800 022 222
- Call the Doctor – 1800 225 584

Note: All care provided to be documented using progress notes

TRANSITIONS OF CARE

When communicating with health care providers use the following process
- I – **Introduce** yourself and the person
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COMMUNICATION

Team members need to:
- Ensure the person dying, family or carers has information in a format accessible to them
- frequently communicate with the disability support worker, carers and **Clinical Case Manager** to determine if the persons health care needs are being met.
- ensure all equipment and resources are in place.
- facilitate case conferencing with **all team members.**

Clinical Case Manager is to:
- communicate and share information with the members of the multidisciplinary team across settings including the Specialist Palliative Care Team (if involved)

MEDICATION MANAGEMENT

Monitor the effectiveness of medications used for symptom control

Refer to GP or Specialist Palliative Care Services if symptoms are not well controlled

A good death

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Diagnosis of life limiting illness | Declining independence | End of life | **A good death**

End-of-life care

Focuses on the persons immediate physical, emotional, cultural and spiritual needs.

The person may be experiencing:

- discomfort
- distress
- irritability
- dehydration
- recurrent fever
- changes in consciousness

Clinical assessment

Is referral required? Y → **Arrange referral**

Consider referring to
- GP
- Medical Specialist
- Specialist Palliative Care Service
- Community nursing
- Psychologist
- Occupational Therapist

N →

All team members need to know the goals for end of life

Communicate findings

Document plan of care in persons notes and Care Plan including the plan for spiritual support.

Share Care Plan with the person, carer, and GP. Ensure plan is accessible by all team members.

Plan for death

Ensure that

Community Nurses are available to provide end-of-life clinical care.

Persons spiritual and cultural needs are met.

Anticipatory **medication** is available to prevent a crisis.

Disability Support Workers are supported and educated to deliver safe, personalised end-of-life care.

Extra support may be needed if the person experiences:

- uncontrollable pain
- distress
- delirium
- infection

Important:

Treatment needs to be provided in accordance with the client's Advance Care Directive or Medical Goals of Care

In any decisions, the persons **needs and wishes** must be the primary focus.

CARER SUPPORT

- The carer may need to be provided with emergency contact details.
- Carers may need access to bereavement support

COMMUNICATION

The most appropriate person is to:

- communicate with **the Clinical Case Manager**, **carer** and **GP** to agree the persons is in the last days of life
- advocate for **the Client and Carer's** needs
- have knowledge of where the client wishes to die to facilitate this if practicable
- communicate with the **Disability Support Worker** and **GP** as frequently as needed
- communicate and liaise with the **Clinical Case Manager** as frequently as needed
- consider any risk such as Carer distress

MEDICATION MANAGEMENT

- Administering medications as per the persons medication chart
- Follow organisational policy and procedures
- Monitor, record and report the effectiveness of medications being used to control symptoms

Note:. All care provided to be documented using progress notes