Palliative care: A shared experience process and practice on waves of change

The Process of recording and documenting a Palliative Care Plan by Robyn Buller CNC.

Every one dies, but we all have a choice for it to be a good death, surrounded by family and friends.

Part of our role as Disability Nurses is to assist our clients to complete the final chapters of their lives with dignity.

Planning

Many of our clients have life limiting illnesses that eventually do not respond to medical intervention.

Often the conversation of No Cardio-Pulmonary Resuscitation order (CPR) and providing comfort care, is initiated in the emergency room, with a Doctor the family has just meet.

This conversation is difficult at the best of times but is probably best initiated with a Doctor the family trusts and has known for some time.

If client has a chronic condition that isn't responding to medical intervention it may be best to document a Palliative Care, Quality of Life Plan, Complex Care Plan or a reasonable name the family may suggest.

The Palliative Care plan does not usually include "No Cardio-Pulmonary Resuscitation order" (CPR) unless a cardiorespiratory arrest can be anticipated. Consultation will be required with Doctor, Person, and family if under Public Guardian they will not consent to Resuscitation Plan (No CPR orders) without a documented medical care plan and each request needs to be reviewed individually.

Alternatively No CPR orders can only be made on a legally binding Advanced Care Directive by a person deemed competent at the time of writing and signing the document.

If no CPR orders are documented the Palliative Care Resuscitation orders will be reviewed each time the client is admitted to hospital these orders will be completed by the attending Doctor in consultation with the person responsible.

Reference can be made to NSW Health –Advance Planning for Quality Care at End of Life –Action Plan 2013 -2018 Page 18 recommends the NSW Council for Intellectual Disabilities End of Life Care fact sheet (2011) For further explanations around Palliative Care Planning

Why do we need a Palliative Care Plan?

All clients living in supported disability residential care deaths are reported to the coroner as per State Legislation covering reviewable deaths in Community Services (Complaints, Reviews and Monitoring) Act 1993. NSW Coroner determines cause of death in relation to people with disabilities in care under the Coroners Act 2009 who will make a decision if autopsy or inquest is required. The death is reviewed as being an expected or unexpected death.

Expected Death

I have discussed with the Coroner what documentation is required to verify an expected death.

The treating Doctor is required to complete a Palliative care letter that details the medical condition, current medical treatment, symptom management and if an anticipated cardiorespiratory will be futile for prolonging clients life, they may include NFR orders .(each client is reviewed individually)

This letter requires regular review for clients with ongoing chronic conditions.

What do we do next after a medical Palliative Care Letter has been completed?

We all have a social, emotional and spiritual aspects to our life and these all have to be included in end stage life planning not just the medicalised aspects of care.

A recent survey was completed that asked allied and medical staff what the most important priorities were for their own deaths,

1. To die in a place of my own choice
2. Adequate and effective pain relief
3. Surrounded by family and friends.

Only difference for our clients is we need to document their preferences on a Plan that includes all their needs.

How do we record clients and families end stage life plans.

Allow ample time for a meeting .Have a trusted staff member attend both the family and client is comfortable with.

I use the ADHC palliative care plan as it covers all aspects of client's lifestyle, It has now been deleted from ADHC Policies but is still recommended by NSW Health in the Advance Planning, End of Life.

I have attached the template as an example but any plan can be developed.

Main areas to consider are

- List of all health care professionals' involved, contact numbers
- Reference to Doctors palliative care letter
- Important family members, friends, advocates and consent source.
- Following needs, physical, social, psychological, spiritual /religious. Future planning for Hospice transfer to hospital.
- Particular requests at time of death any religious rituals, family needs.
- Have person responsible to sign the plan

Who requires copies of the plan?

- Placed in client records.
- Residential Management.
- Person responsible.
- Copy of Doctors letter can be added to" eHealth record systems.

- Complete a hospital booklet with copies of Doctors letter, Palliative Care Plan and NSW Authorised Adult Palliative Care Plan.

In event of expected death complete a NSW Ambulance Authorised Adult/Paediatric Palliative Care Plan

Plans are completed by a Medical Officer.

Consent obtained from Client or person responsible (including Public Guardian)

Decisions around resuscitation are documented on the plan.

The plan is endorsed by NSW Ambulance and remains in effect for 12 months or if a review is required.

Location of care can be requested if a particular Hospice has been allocated.

Paramedics are able to administer 32 medication via various administration routes.

Notification to the Coroner can be included in the post death plan.

Paediatric Plans require Department Family and Community Services to be notified of the Palliative Care Plan and at time of death.

Group Home Staff Palliative Care Planning Meeting

Group home staff will require some sessions to discuss concerns and processing of documentation.

Member of Palliative Care Team if available.

I recommend attending with a therapist who is experienced in end of life discussions.

Common fears of all staff as per research is as follows

1. Not knowing what the death process looks like or what to expect.
2. Fear of not knowing what to say to client or families.
3. Anxiety around breaking bad news to the relatives and staff's own reaction to client's death.
4. Finding client dead when you are on your own.
5. Not knowing how to support other clients during end of life care and at time of their death.
6. The Coroners findings and the death review documentation by the Ombudsman.

All staff need time to express their own stories around death to understand how they will care for the client.

All organisations have Counselling services for staff and they should be encouraged to access them for ongoing support as required.

Access and discuss community supports for staff and the client.

Have easy accessible telephone numbers of all the contacts that will be able to answer questions, concerns for both staff and family members.

Encourage use of Palliative Care Ambulance services, Palliative care team.

Provide end of life care education, on line training modules, reference material.

Clear flow charts need to be in place around expectations of staff at time of client's death.

- Informing Police and ambulance if death occurs at home.
- Importance of leaving client as they found them not to move the person, remove any devices medical equipment from the body .Leave clients bedroom intact until Police authorise removal of body to the Coroners Morgue.

Group Home Documentation

All staff need to review all clients' plans, procedures medication charts, financial statements to see they all comply with the organisations practice standards before the client's death.

After clients death all documentation is removed from the group and home as per Legislation requirements.

Other Clients residing in the Group Home will require ongoing Supports.

Other clients will need therapy supports so information can be delivered their level of comprehension.

Grief counselling will be required before and after the death for some clients.

Funeral Planning, any assistance required in Funeral Service

Some family members request all the staff and clients to be involved in the funeral planning and service .Others may want a private family service.

If a client is under the NSW Public Trustee without family involvement it is worthwhile contacting them before the death to organise funeral details.

If staff are requested by family to supply stories, pictures for the service it is highly recommended all these details are finalised before the death as grief reactions will be different in each staff member.

At the time of death

All deaths in disability supported accommodation and clients temporarily accessing hospitals or aged care respites will come under the care of the coroner.

Police services will need to be contacted regardless of where the death occurred.

Police will request to talk to last person who saw client alive .This is not a forma police interview only information gathering.

Police are acting on behalf of the coroner and have the authority to request copies of any documentation.

Ombudsmen death reviews

NSW Ombudsman is responsible under Complaints, Reviews & Monitoring Act 1993 to review all deaths of people who died while they were living in respite & residential care funded by disability services.

This includes Government, NGO's and not for profit organisations.

Exemptions being if client lives at home with family and is not accessing any supported external accommodation.

Focus of reviews is to identify any factors that may contribute directly or indirectly to deaths that may be preventable.

These reviews enable the Ombudsmen to identify any trends in health and risk management on a state level so recommendations can be made to improve disability services.

This information is collected by completing a Ombudsman client death notification form within 48 hours of the death.

Management will request all the clients documentation is sent to a secure storage area.

Ombudsman may request documents over several months during the review reports.

During Ombudsman reviews they may find some discrepancies with documentation and request to interview staff. This is a fact finding interview and is in not disciplinary.

Occasionally an external reviewer may want to interview staff to clarify written documentation or specific client care practices.

Internal death reviews

Organisations will complete their own internal death reviews to inform practice leaders and policy directorate of any changes required to processes.

Some organisations will employ the services of an external reviewer /investigator to maintain quality control within the service.

Grief reactions for staff, clients, families and external service staff.

Everyone reacts to grief in their own personal way .This is informed by personal experiences, cultural, educational and spiritual backgrounds to name just a few.

Over the years I have reassured people that grief will make us all review our past losses, not necessarily always the deaths of loved ones.

This is a time for people to accept colleague's differences, provide counselling services and allow people to choose their own coping strategies.

Quote

"Sometimes you will never know the value of a moment until it becomes a memory."

Dr Seuss

References

Legislation

Community Services (Complaints, Reviews and Monitoring) ACT 1993

Coroners Act 2009

Disability inclusion Act 2014

Decisions relating to Resuscitation Plan (No Cardio-Pulmonary Resuscitation (CPR) Orders) Resuscitation Plans in End of Life Decisions –NSW Health 2017

Advanced Care Planning Australia (2016) Substitute Decision Maker.

NSW Health –Advance Planning for Quality Care at End of Life –Action Plan 2013 -2018 Page 18 recommends the NSW Council for Intellectual Disabilities End of Life Care fact sheet (2011) for further explanations around Palliative Care Planning.

Ombudsman NSW 2012 Reviewable Deaths Community Services Information Sheet. State Legislation covering reviewable deaths in Community Services (Complaints, Reviews and Monitoring) Act 1993. NSW Coroner determines cause of death in relation to people with disabilities

Deceased Estates: 2012 NSW Trustee an Guardian Fact Sheet no 13

NSW Agency Clinical Innovation. 2013 Report to inform the model of care for Palliative and End of Life Care Service Provision

NSW Ambulance Authorised Adult Palliative Care Plan {Electronic version)

Dr A Jadard, 2017, Keynote Speaker, Palliative Care Australia, 15th Annual Conference South Australia

Margaret Umbrich: 2017 Keynote Speaker, Palliative Care Australia 15th Annual Conference South Australia