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Invited Seminar on EoLC in Vulnerable Groups

# End of Life Care Services for Persons with Intellectual Disabilities (PIDs)

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尊嚴、自在，擁抱夕陽

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# Concept of Death (McEvoy, MacHale,& Tierney 2011):

**Universality (廣泛性) & Inevitability(不可避免)**

none can escape from death.

The Society has discrimination, but DEATH doesn't.

Persons with disabilities' needs of
EoLC services
should not be ignored.

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TWGHs Jockey Club Rehabilitation Complex
4, Welfare Road Aberdeen, HK.

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# Since 2007, we provide Comfort Care Services for

- Aged Blind;
- Persons with Intellectual Disabilities;
- Severely Disabled Persons with terminal illness

- Late stage Cancer
- Non-cancer: such as Organ Failure、late stage Dementia.

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# Collaborate with the Palliative Medicine Unit of Grantham Hospital

- 6 Care & Attention Home for Aged Blind
- 7 Day Activity Centre cum Hostel for Persons with Intellectual Disabilities.
- 4 Care & Attention Home for the Severely Disabled Persons
- 2 Hostels for the Moderately Mentally Handicapped Persons

**SOCIAL SERVICE**
**&**
**MEDICAL SERVICE**
**COLLABORATION**
**(醫社合作)**

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殘疾人士安寧照顧服務

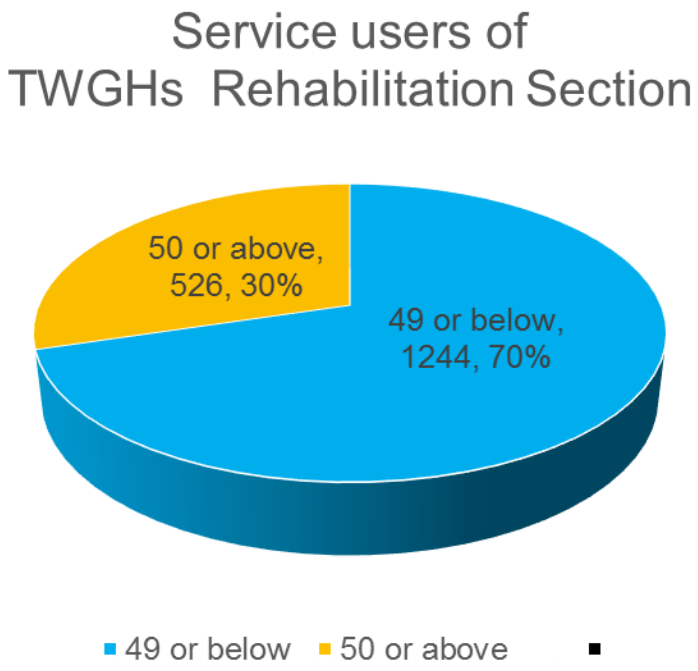
# Comfort Care Service for Persons with Disabilities


A Protocol is jointly developed by TWGHs & GH over the years

熱愛生命 、 尊嚴自在 、五全照顧 、擁抱夕陽

# Issue of Double Ageing

Both *Persons with Intellectual Disabilities (PIDs)*and *their Parents* face the challenges of ageing, death & dying.



- How to support PIDs to face their own death & dying.
- How to support PIDs to face their parent's death & dying.
- How to support PIDs' parents to face PIDs' death.

- These needs always here, the issue of double ageing raises the concern to the EoLC services for them.

# Do PIDs understand what Death is?

- Collaborate with Dr Amy Chow, The Dept. of Social work and Social public Administration, University of HK (2013)
- The Study of the needs of Life and Death Education and bereavement care of PIDs in HK

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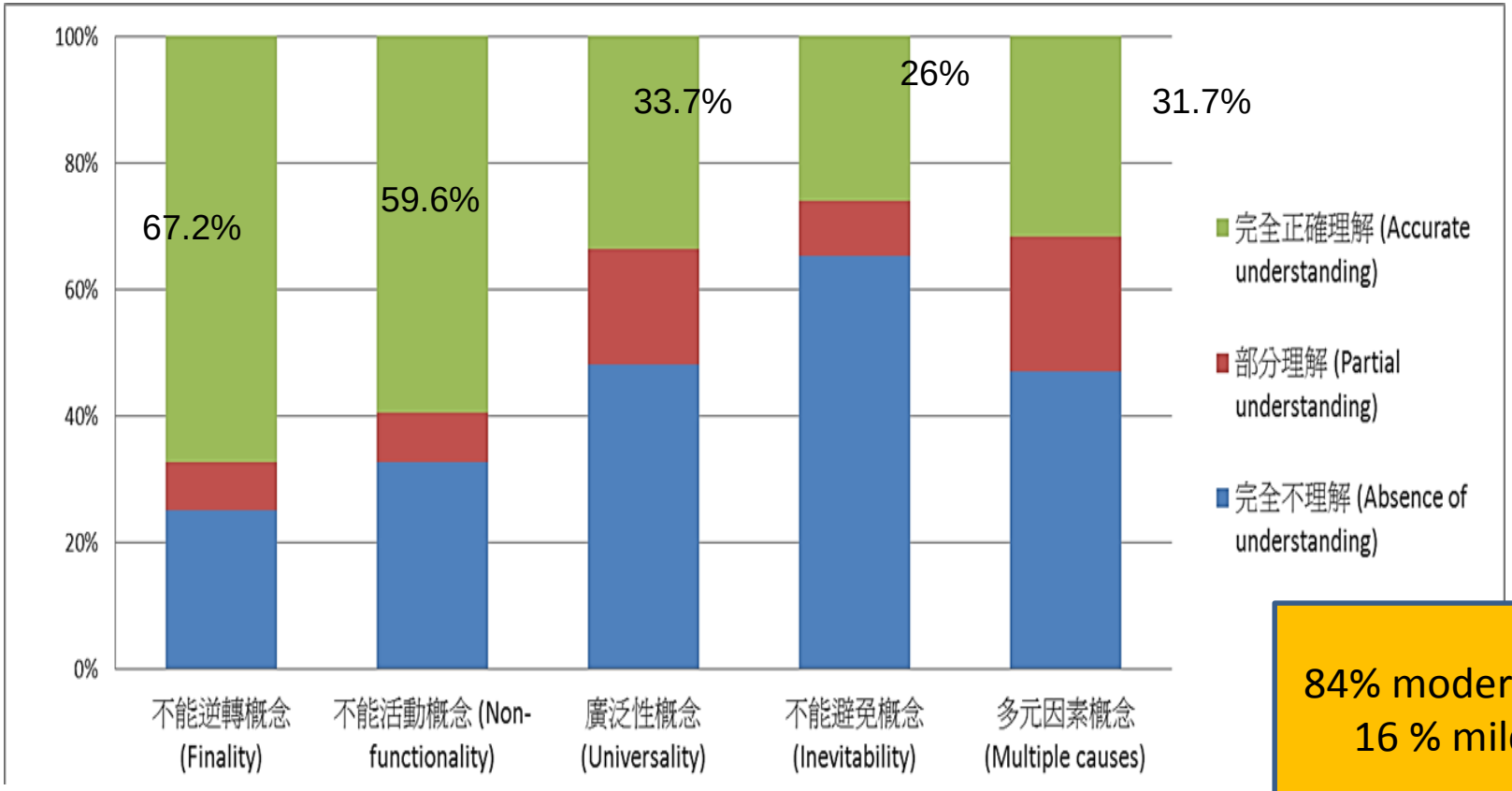
# The concept of Death (N=104)




84% moderate ID;
16 % mild ID

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If some PIDs don't understand

just stop or…… **to educate**

# We need to clarify

- They *don't understand* or *have difficulties in communication* ?
- Or do we have patient to hear their voice.

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# They are Mentally Incapable Persons (MIP)

- Legally, they don't have the right for making decision on their own, such as Advance Directives.
- But do they have the right to know what might happen, and to express their will?

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# Advance Care Planning (ACP) for PIDs

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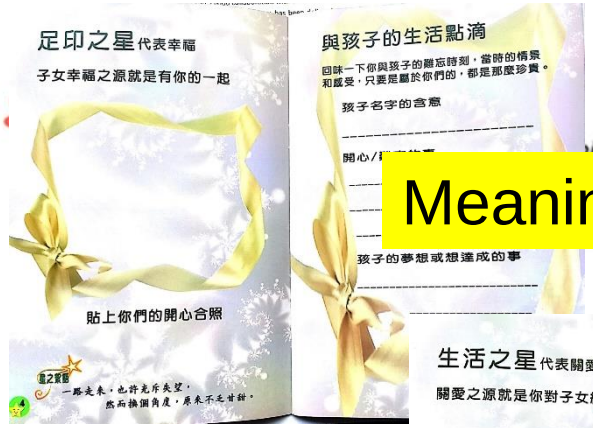
# Process of conducting ACP

- 1st Promotion and Education
- 2nd Introduce Stars & Wishes booklet to help PIDs & Parents understand ACP in a easier & more user friendly way.
- 3rd Engagement & go through the booklet (get prepared)
- 4th To meet Doctor to discuss and to conduct ACP.
- 5th To follow up and Implement.

**Exploring a Good practice for conducting ACP**



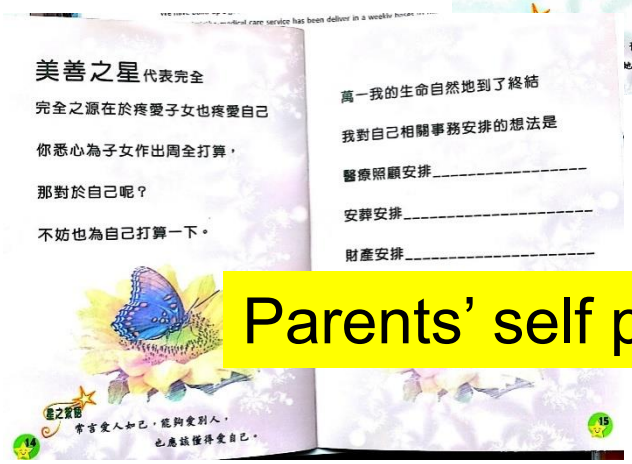

Meaning of Life


Continue
Support for living


Life style & habits


Medical Care


Funeral arrangement




Parents' self planning

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# Aims

- To use simply way to facilitate Parents, PIDs & Professional Caregivers to have communication about EoL care planning.
- To inspire parents to have a comprehensive view about their son/daughter's needs.
- To stimulate parents consider also to their own needs.

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- To facilitate PIDs to involve into the process of planning as much as possible.
- Caregivers, family take part in the planning **according to their understanding** to the PIDs, and also **for the best interest** of them.

# Palliative care for the patients with intellectual disabilities

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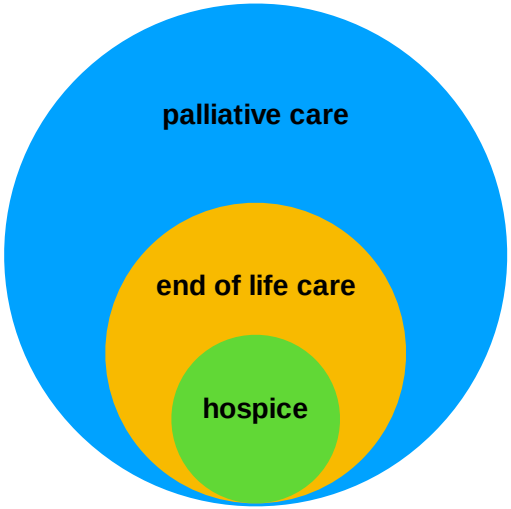
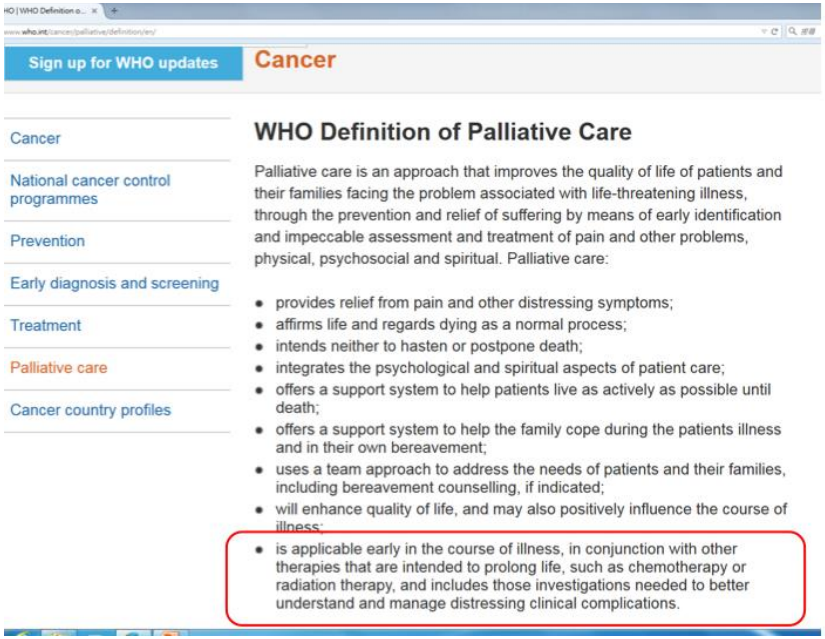
# Palliative care is much more than just end-of-life care




**Taxonomy of palliative care**



Sign up for WHO updates

Cancer

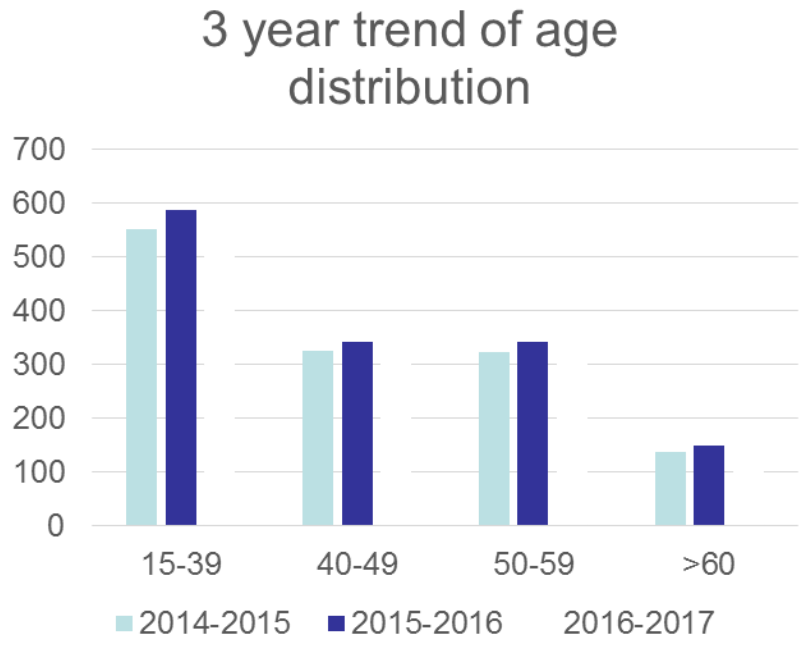
- Cancer
- National cancer control programmes
- Prevention
- Early diagnosis and screening
- Treatment
- Palliative care
- Cancer country profiles

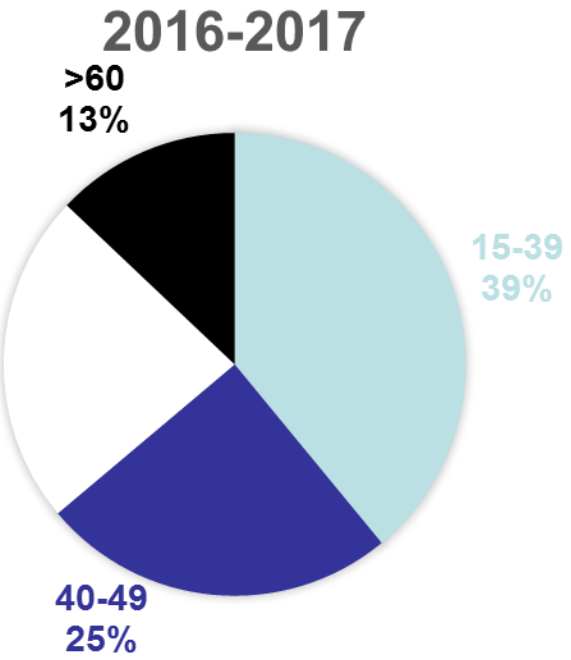
## WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

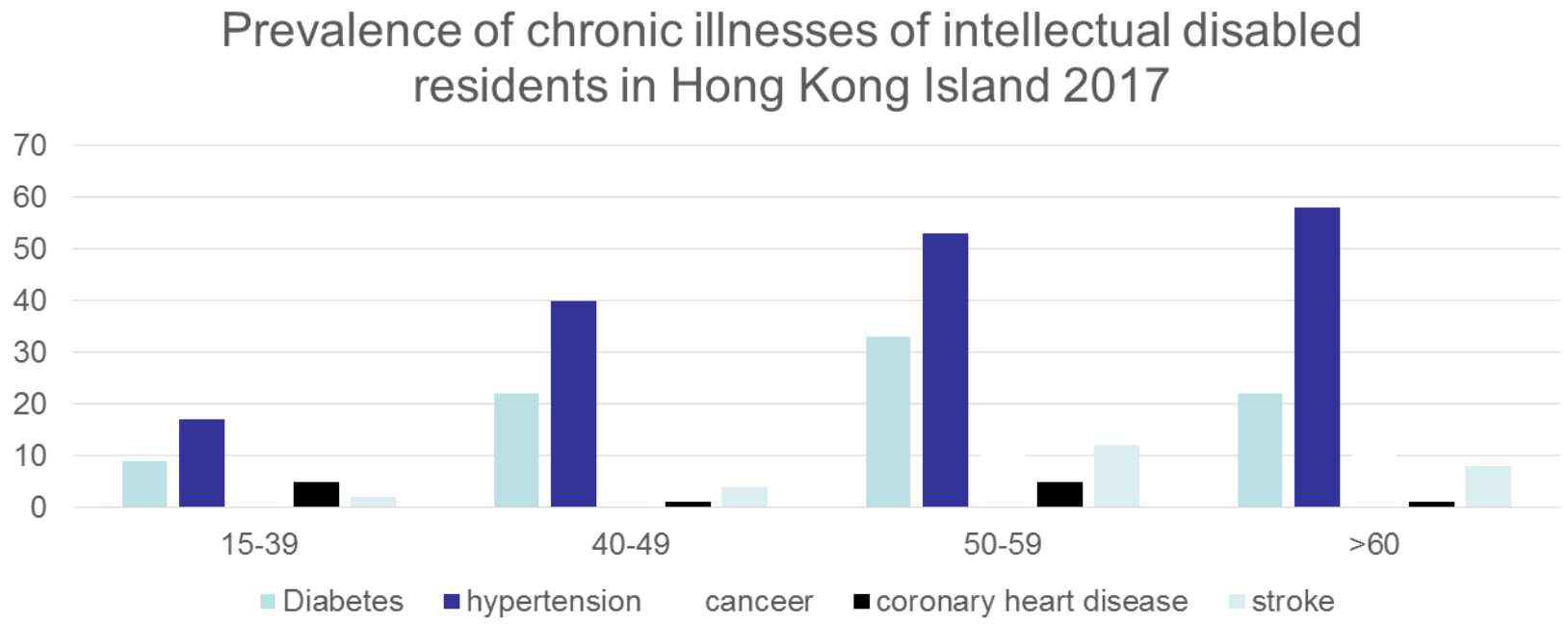
# Aging population of the intellectual disabled




Age distribution of clients with intellectual disabilities in Hong Kong Island

# Increasing prevalence of chronic illness with age



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Seamless delivery of palliative care with interface between the health care sector and social sector to provide holistic care to patients through out the illness trajectory

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# Concerted efforts of the Multidisciplinary and Interdisciplinary Palliative care team

## Grantham Hospital PC team

- PC specialist doctor
- PC home care nurse
- Hospital medical social worker

## Community PC team in JCRC

- Social worker
- Link nurse
- Volunteers

Referral criteria :

- Surprise question : " are you surprised client will pass away by next year ? "
- Recurrent admissions to hospital
- Remarkable deterioration in general condition
- Family stress e.g. complicated grief, dilemma of treatment decisions etc

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# Outreach PC team

- Hospital PC team assesses patient in the residential home where patient lives , patient feels more at ease and less stressful
- Patients and family can be seen in their familiar environment, with the care-team readily available to offer collateral information and instant support
- Clear direct face to face communication between the hospital PC team and the informal and formal care givers in the community to facilitate holistic understanding of patient and his family dynamics

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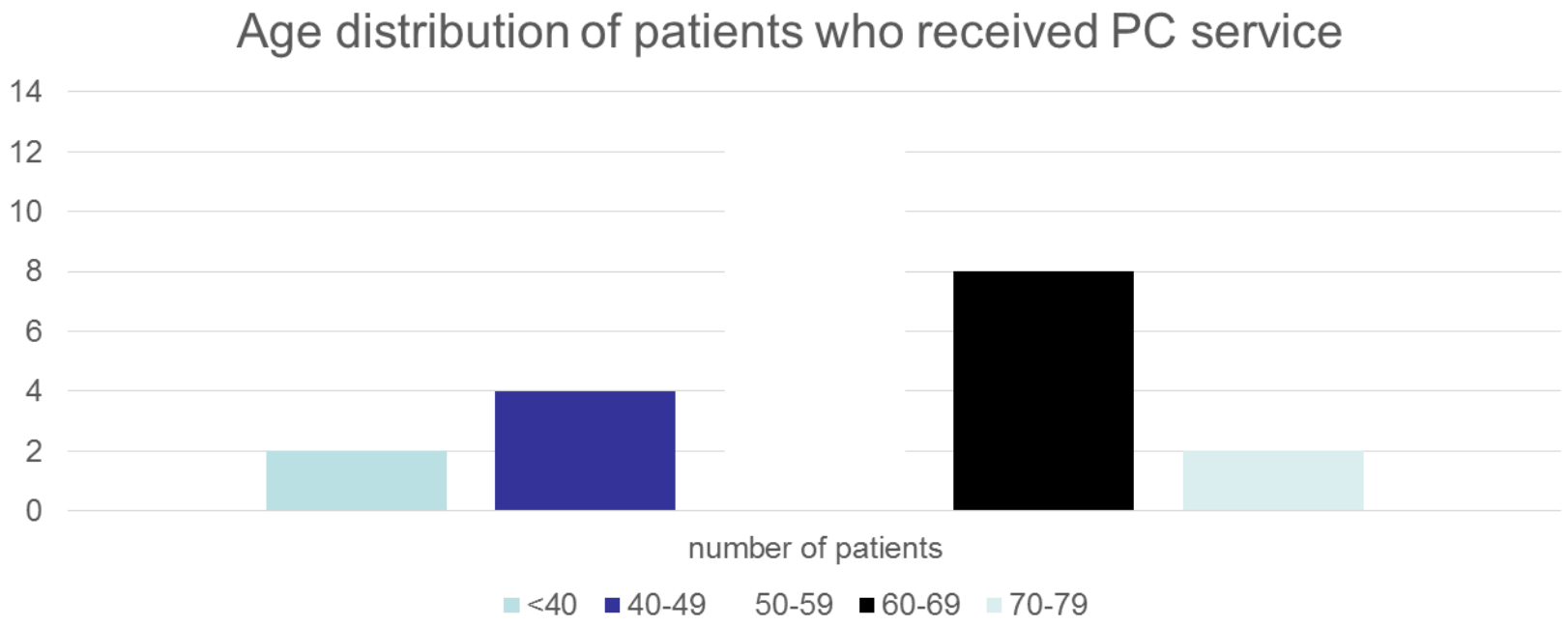
# Most patients who received the service are 50 years or older




(2008-2018) Patients with intellectual disabilities who received specialist palliative care (PC) before death , Grantham Hospital and JCRC experience

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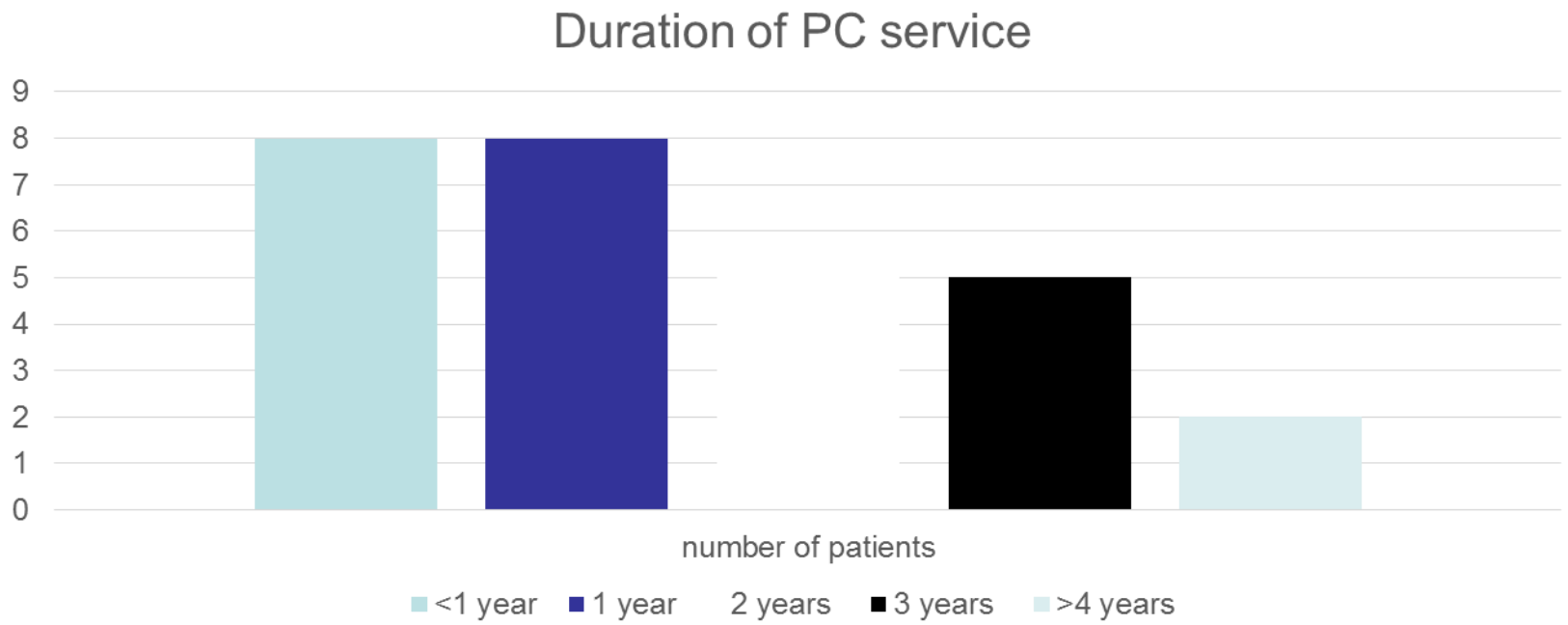
# Most patients who received the service died within 1 to 2 years, while some patients receive the service for longer duration




(2008-2018) Patients with intellectual disabilities who received specialist palliative care (PC) before death , Grantham Hospital and JCRC experience

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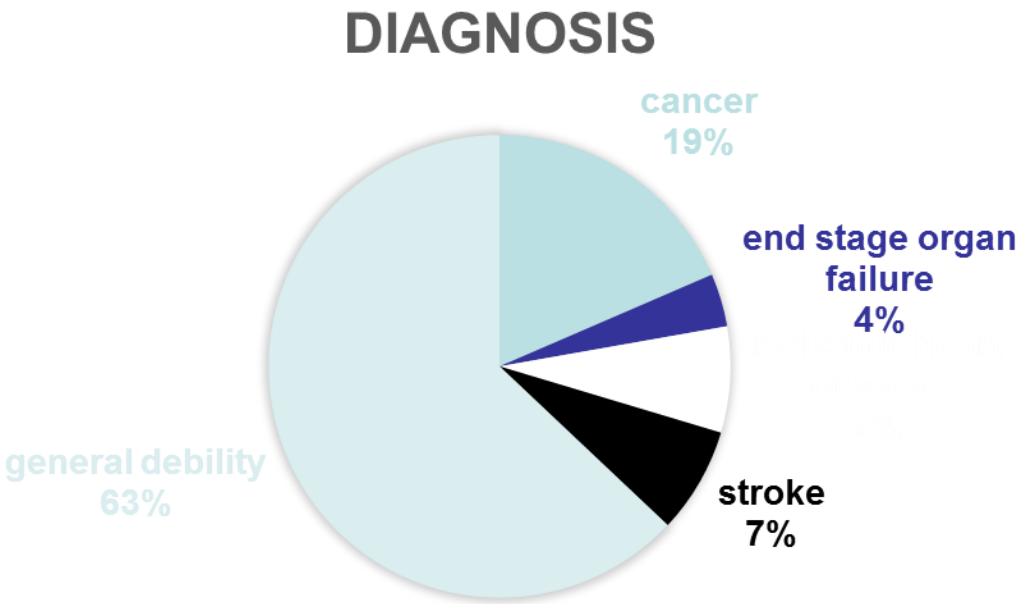
# Most common trigger for referral was remarkable general condition deterioration and debility




(2008-2018) Patients with intellectual disabilities who received specialist palliative care (PC) before death , Grantham Hospital and JCRC experience

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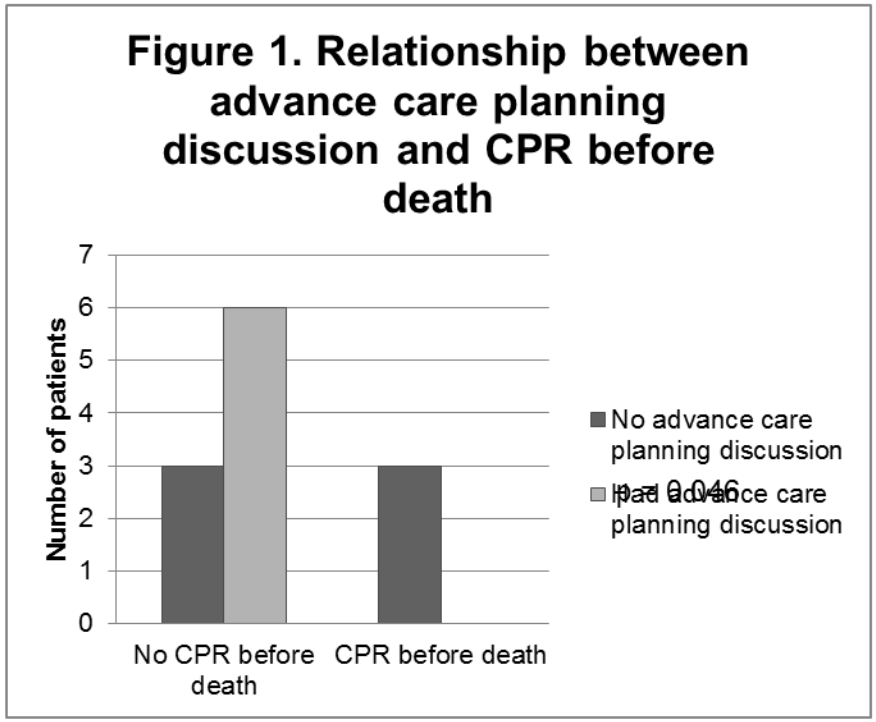
Retrospective review of case records of ID patients referred for palliative care services from January 2008 to August 2014

- 24 patients (54.2% male) were followed up for a median of 22 months ( range 1 to 74 months ).
- Mean age of patients was 50.3 (SD 11.7).
- Mean number of symptoms was 2.2 (SD 1.2),
  - which included pain, constipation, weight loss, skin wound, spasticity and edema.
- 38% of family main carers expressed sadness and helplessness on initial assessment.

**Palliative care for patients with intellectual disabilities: if not, why not?**
**Review of collaborative palliative care service for patients with intellectual disabilities in a long term care residential home**
Li et al Oral abstract . Asia-pacific Hospice Conference APHC 2014

- 38% of patients and families had advance care planning (ACP) discussed
  - which included end of life issues, identification of goal of care and cardiopulmonary resuscitation (CPR) preference.
- All of them (100%) expressed the wish of declining CPR.
- ACP discussion was associated with no CPR done before death (p=0.046 , figure 1 )
- Half of the patients died during follow up.
- The main cause of death was infection (68% ).




**Palliative care for patients with intellectual disabilities: if not, why not?**
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- As of March 2018
  - 23 patients actively followed up by the PC team of Grantham Hospital
  - 28 patients passed away
  - 8 ( 28% ) passed away in Grantham Hospital Hospice

# Systemic review (2017) on ACP for Patients with intellectual disabilities

- A total of 14 studies were included.
- Most studies examined the perspective of professionals and/or relatives.
- None of the studies focused on the perspective of patients with ID.
- The studies concerned different elements of ACP, mainly decision-making and organizational policies.
- No effect studies were found.
- Obstructing factors were difficulties in recognizing palliative needs and uncertainties among relatives and professionals about their roles and tasks in ACP.

1.Journal of Pain and Symptom Management, Volume 54, Issue 6, December 2017, Pages 938-960.e1

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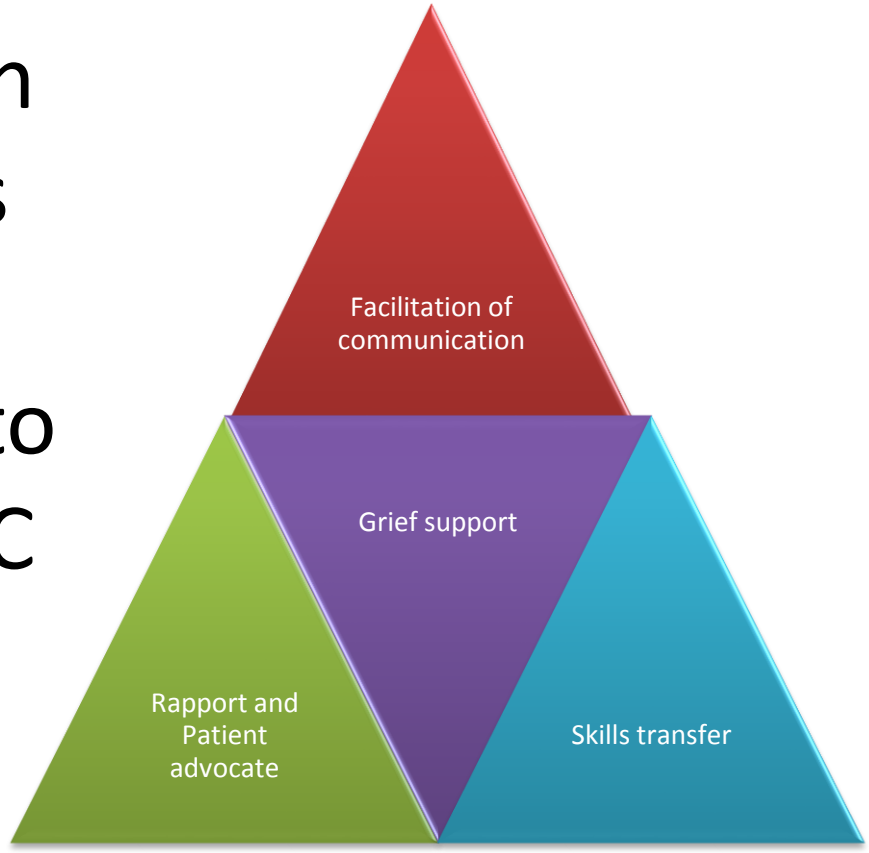
Collaboration between medical professionals and social welfare professions is the key to effective delivery of PC service



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# Wish List

- EoLC services should be **for ALL**.
- Further to Residential setting, disabled persons **living in the community** should also be care for.
- More education and Training should be provided to social & medical practitioners **to understand the needs** of EoLC service of PIDs , and **to enhance skills in communicate** with them.
- A **good practice** of the process in conducting Advance Care Planning should be promoted.
- **Collaboration** between Medical Service and Social Service should be **strengthen**, as it is the **key to provide quality EoL Care** for people having terminal illness.