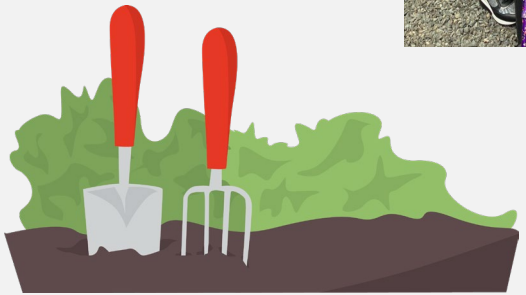
How exploring the social determinants of health can improve care and support for people with a life-limiting illness.

Professor Audrey Roulston

1st February 2024

Who am I?


EAPC
EAPC 2023
European Association for Palliative Care
18th World Congress
EQUITY & DIVERSITY
#EAPC2023



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PgDip | Postgraduate Taught

Palliative Care

Entry year
2024/25

Entry requirements
Bachelor Honours Degree

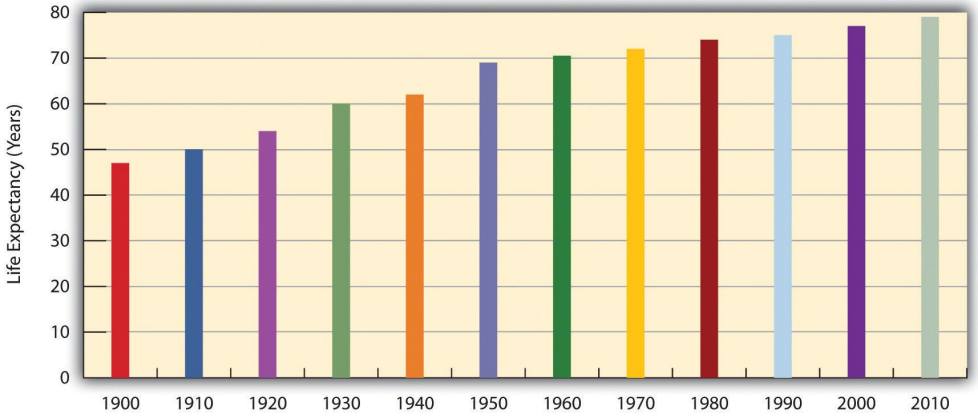
Duration
2 years (Part Time)

Places available
20 (Part Time)

Apply now

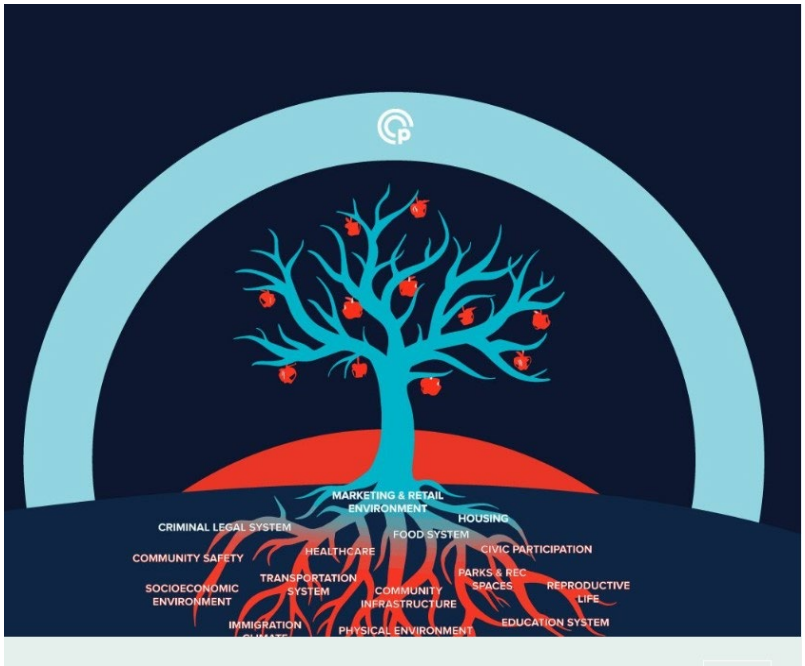
Social Determinants of Health

The Social Determinants of Health (SDH) are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life **(World Health Organization, 2024).**



- Poverty / income
- Housing / environment
- Health behaviours or lifestyle choices (alcohol, tobacco, drugs)
- Access to good health care services
- Work or personal stress
- Early childhood experiences
- Unemployment/job security
- Education
- Secure access to food
- Social exclusion
- Transport
- Community environment
- Social support networks
- Socio-economic position
- Structural / political context

Social Determinants of Health (Marmot, 2005)



https://www.thepraxisproject.org/social-determinants-of-health

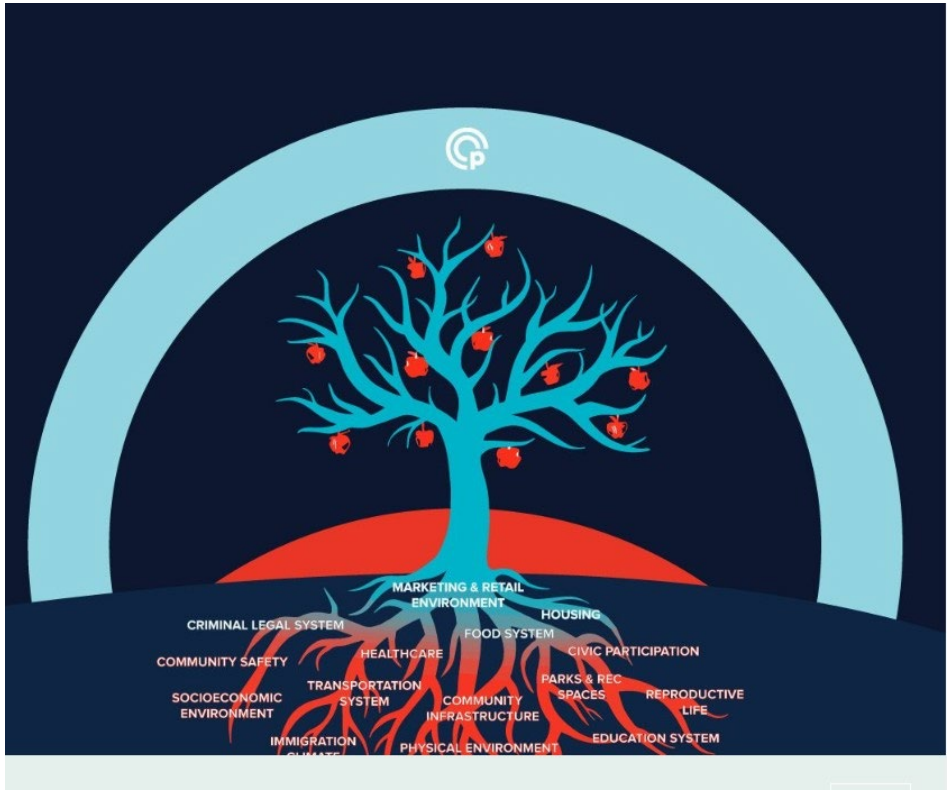
1. Soil = racism, sexism, ableism, capitalism, homophobia, etc are systems reinforced by policies or legislation to oppress groups.

2. Roots, trunk and fruit = food / transportation / education / housing systems, community safety, immigration climate, community infrastructure, healthcare, etc.

3. Shovels = uprooting corrupted soil and promoting healing, community-based approaches, advocacy and helping people regain power over their lives.

4. New Soil = removing oppression and working towards building and imagining a new world where oppression is removed, wealth is redistributed, communities are interdependent, and policies and practices do not oppress minority groups.

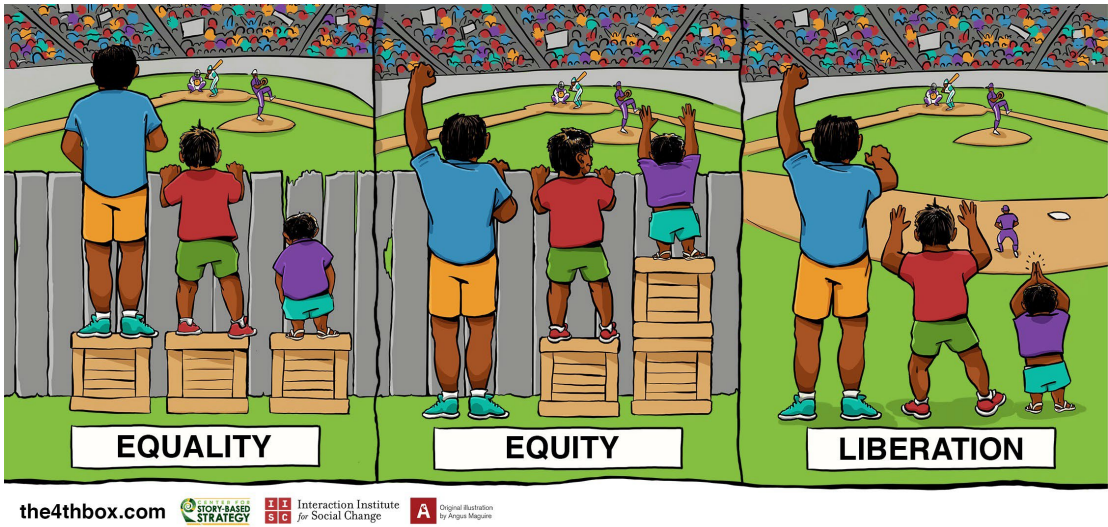
5. Healthy people and communities = liberation, justice, equity, dismantling systems of oppression. Cultivating equitable and healthy people or communities.



Key Factors

People's living conditions are often made worse by discrimination, stereotyping, and prejudice based on sex, gender, age, race, ethnicity, or disability, among other factors.

Discriminatory practices are often embedded in institutional and systems processes, leading to groups being under-represented in decision-making at all levels or underserved.



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Health inequalities, refer specifically to differences in health between social groups that have three distinguishing features: (Whitehead and Dahlgren, 2006).

- They are systematic: they are not random but follow a consistent social pattern.
- They are socially produced: not the result of biological or other fixed processes and are modifiable.
- They are widely perceived to be unfair or inequitable.

Care Quality Commission (2016)

A different ending: Addressing inequalities in end-of-life care.

The Care Quality Commission identifies several groups for whom inequality is observed at the end of life:

- people with conditions other than cancer
- older people
- people with dementia
- people from Black and minority ethnic (BAME) groups
- lesbian, gay, bisexual and transgender people (LGBTQ+)
- people with a learning disability
- people with a mental health condition
- people who are in secure or detained settings (prison)
- people who are homeless
- Gypsies and Travellers

Palliative Care for LGBTQ+

Some people who identify as LGTBQ+ may have experienced hostility or stigma associated with prior legal status.

Some individuals may refuse care from organisations affiliated with religion/church.

Partners may struggle longer to avoid having carers coming into their home and may feel isolated and unsupported.

Always obtain consent prior to sharing information on a person's sexual orientation.

Avoid making assumptions about biological family knowing preferences vs family of choice

Use inclusive or neutral language (partner vs spouse and people important to them vs NoK)

Fears of being rejected or discriminated against by staff once identity is known.
Fears of being affectionate in front of others in case of negativity.
Transgender individuals may fear not being buried as correct gender.

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Palliative Care for Prisoners

Most prison cells are inappropriate for end-of-life care: equipment, staffing, noise, relatives unable to visit dying person.

Very few prisons have palliative care wings or 24 hour medical/nursing care onsite.

Barriers to accessing palliative care due to:

- hospital appointments being cancelled
  - inadequate secure transport
  - no prison staff to escort prisoners
- delays in diagnosis, treatment or care.
- security procedures delaying in-reach services from specialist pall care team
- limited drug regimes for pain management
- applications for compassionate release seldom processed on time / approved

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Challenges in practice:

Derogatory comments / discrimination by staff
Lack of compassion or inappropriate use of restraints
Balancing care and control of prisoners
No ACP … where is home?
Some prisoners prefer to die in prison, are estranged from family or have no where to go upon release…

Palliative Care for Homeless People

People who are homeless die younger

(39-42 Females / 43-46 Males in UK)

Higher risk of **tri-morbidity**: physical health issues (heart, lung, liver or renal disease, stroke, diabetes or cancer) and mental health issues and substance use disorders.

Barriers to routine health care due to:

- limited interaction with health care staff
- hostel/outreach staff unaware of palliative care services/referral process
- discrimination based on lifestyle

Fear losing their independence, being a burden to others, wishes being unknown, dying alone, no-one to identify their body, etc.

Explore the person's needs in the **context** of trauma, fear, addiction, mistrust, discrimination, limited social support, poverty, etc.

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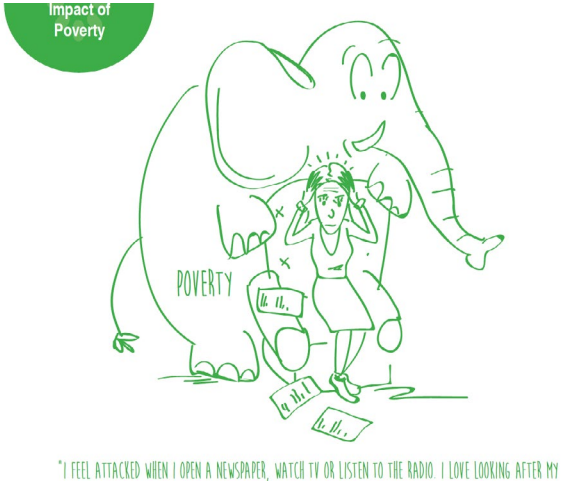
https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-018-0320-6

Poverty



What do we mean by poverty?

"When a person's resources are not enough to meet their basic needs and allow them to take part in society. This could mean struggling to cover food and energy bills, watching every penny spent, worrying that nothing is set aside for a sudden emergency such as the cooker breaking down, or being unable to afford the cost of transport needed to visit a friend or go to a social club" (Age UK, 2015).

Poverty at the end-of-life (UK)

Stone and Hirsch (2022)

In 2019 there were 90,000 people who died in poverty (UK wide)

Higher percentage of people in poverty for the last year of life were:

Working age (20-64 years) 27.6% vs pension age (65+) 13.4%

Women of working age (28%) vs males of working age (26.7%)

BAME of working age (42.6%) vs White of working age (25.4%)

Non-cancer patients (31%) vs people with cancer (21%)

Why?

- Person with life limiting illness and carer/partner may be unable to work…family rely on benefits.
- Fuel poverty – rising fuel costs plus person at home feels colder due to illness.
- Rise in cost of food, rent, mortgage rates, transport costs to access treatment, childcare costs, etc.
- Being newly diagnosed and leaving work substantially increases risk of dying in poverty.

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https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-poverty-at-the-end-of-life-in-the-uk-2nd-pp.pdf

Different types of Poverty (deprivation)

Nutrition

Water

Sanitisation

Clothing

Housing

Education

Health

Information

Play

Higher rates of poverty in households where:

- Migrants and Minority ethnic groups vs White live
- Social renters (43%) or private renters (35%) vs homeowners (15%)
- Someone has a disability (24%) vs no one with a disability (14%)

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Some of Ireland's most excluded groups experience mental health and stress difficulties. There is evidence that Travellers, lone parents and asylum seekers experience stress, depression or mental health difficulties linked to discrimination, stigmatisation and poor living conditions (Combat Poverty Agency, 2007b:17).

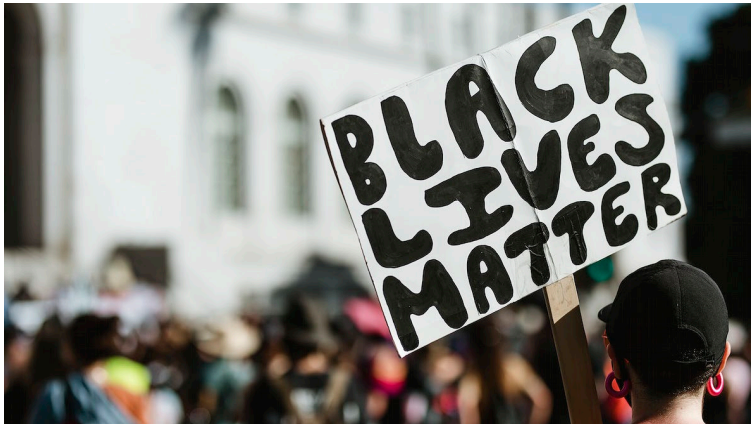
Stress leads to physical ill-health through biological pathways, by affecting the immune system (Dahlgren and Whitehead, 2006).

Alcohol and drug related indicators continue to show some of the largest health inequalities monitored in NI, (DH, 2018 Health Inequalities-Annual Report).

https://www.health-ni.gov.uk/news/health-inequalities-annual-report-2018

Marmot Review 10 years on (Feb 2020)

- Illustrated improvements in health (based on life expectancy and mortality) had slowed since the 2010 Marmot report
- Health inequalities had grown between 2010-2020
- Life expectancy of men and women in the most deprived areas, outside London, had dropped
- Housing conditions had dropped (overcrowded and poor-quality housing) and costs had increased (i.e. rent for private and social housing)
- Yet, in 2018, British Prime Minister Theresa May declared that austerity was over!
- Structural racism: report emphasized the need to deal with such racism in combatting the social determinants of health inequalities.



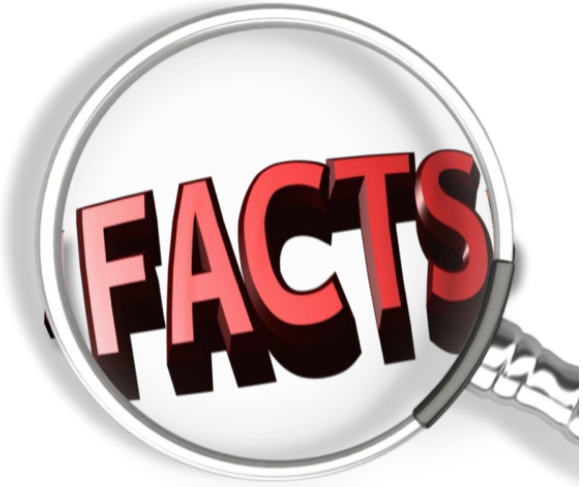
https://www.instituteofhealthequity.org/resources-reports/marmot-review-10-years-on

The impact of COVID

- When COVID-19 hit…health inequalities widened
- The wealth of America's billionaires increased 29%. Hourly wages of the bottom 82% of the population decreased by 4%.
- Government policies reduced public expenditure: cuts to adult social care and public health funding, cuts in welfare to families with children and to education.
- Impact of COVID-19 on access to healthcare, housing, education, employment, social support or food, and the impact of COVID-19 on debt, mental health, social isolation, domestic abuse…
- Rough sleeping & families in temp accommodation increased
- Number of people smoking decreased during first lockdown, but sharp increase of the number of people high risk drinking

Key facts about palliative care

- Each year, an estimated 56.8 million people need palliative care.
- Worldwide, only 14% of people who need palliative care currently receive it.
- The global need for palliative care will continue to grow due to the ageing population
- Palliative care should be available to all, irrespective of geography, social circumstance, place of care, illness and ethnicity.
- It improves the quality of life of patients and their families, who are facing challenges with life-threatening illness (physical, psychological, social or spiritual)



- Access to palliative care should be recognised as a human right (Laird et al., 2021). Access to care to ease pain and suffering is a human right (Gwyther et al., 2009).
- Integration of palliative care into national healthcare services is essential for each country to develop sustainable palliative care services to all who need it.
- Globally, in 2011, only 20 countries had integration of palliative care into their main healthcare service…highlighting vulnerability of services, and limited sustainable infrastructure (Lynch et al., 2013).
- World Health Organisation (WHO) stated palliative care is an essential part of healthcare and should be accessible in all countries (Laird et al., 2021). https://doi.org/10.1093/med/9780198821328.003.0008

World Health Organisation: Goal

The UN Decade of Healthy Ageing (2021–2030) seeks to reduce health inequities and improve the lives of older people, their families and communities through collective action in four areas:

1) changing how we think, feel and act towards age and ageism;
2) developing communities in ways that foster the abilities of older people;
3) delivering person-centred integrated care and primary health services responsive to older people; and
4) providing older people who need it with access to quality long-term care.

- https://www.who.int/initiatives/decade-of-healthy-ageing

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How can we improve care and support?

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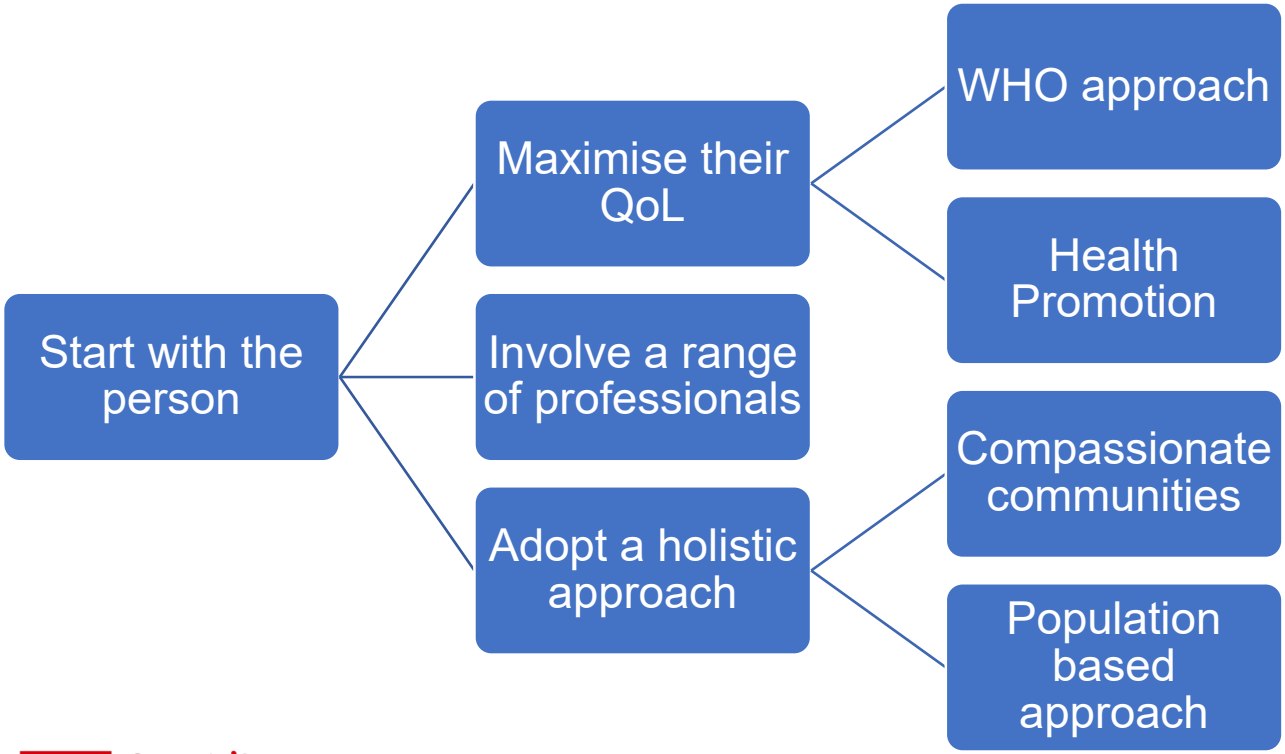
A public health approach to palliative care



Policies, drug availability, education of HCWS & public, implement PC throughout society based on culture, system & economic situ.

Mobilise community resources, train volunteer befrienders, educate children & adults ref death / dying, improve awareness / education for ACP, wills, death literacy

Use a community development approach to meet needs of the community. Build trusting relationships. Caring for people is everybody's responsibility.

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https://aiihpc.org/wp-content/uploads/2015/02/Briefing-Paper-Public-Health-Approaches-to-Palliative-Care-Nov-2017.pdf

In conclusion…

See the person…not the label

Prioritise the needs of those most vulnerable

Identify and challenge oppression at all levels

Work as a team to overcome barriers to treatment / care

Uphold ethical practice and promote human rights

Educate individuals, colleagues, communities, teams, the public

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