AIIHPC

All Ireland Institute of Hospice and Palliative Care

"Improving the palliative care experience across the island of Ireland"

Occupational Therapy and Physiotherapy in Palliative Care

Contributors

Marymount
University Hospital & Hospice

GALWAY HOSPICE
MAYO HOSPICE

South East
Palliative
Care

Our
Lady's
Hospice
& Care
Services

Respite
Rehabilitation
Reassurance

Harold's Cross
Blackrock
Wicklow

LauraLynn
IRELAND'S CHILDREN'S HOSPICE

THE MATER
HOSPITAL

Milford Care Centre
(Under the auspices of Little Company of Mary)

Dignity | Respect | Compassion | Collaboration | Excellence | Kindness

St. Francis Hospice Dublin

OVERVIEW

What is Palliative Care?

Role of physio and OT

Palliative care myths!

A “Day in the Life”

Transferable skills

Student experiences

Patients’ Voices

Case studies

Q & A

What is Palliative Care?

Simone Sheehan

Palliative Care

"You matter because you are you,

and you matter until the last moment of your life.

We will all help you,

not only to die peacefully but to live until you die"

Dame Cicely Saunders

Palliative Care Philosophy

Role of Physio and OT

Simone Sheehan and Sandie O’Brien

Role of OT

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WFOT position statement..

- Death is an unavoidable and natural conclusion of life, and OTs have a unique role in supporting participation in desired occupations for people who are dying and their families.
- Individuals approaching the end of life may experience decline in body functions and structures over time, <u>but not a loss of right to life participation</u>.
- Regardless of clients' life expectancy, OTs provide a unique service that enables function, comfort, safety, autonomy, dignity and social participation through engagement in occupation.
- OTs have a unique contribution through skills of
  - Analysing tasks
  - Modifying activities
  - Adapting the environment

  Thus minimising potential barriers and maximising strengths.

Wellbeing
Spiritual
Physiological
Neuro-behavioural
Person
Cognitive
Psychological
Occupation
Occupational performance and participation
Performance
Quality of Life
Social Support
Economic Systems
Environment
Culture & Values
Built Environment & Technology
Natural Environment

Occupational Therapy Approaches

Manage temporary / permanent functional limitations:

Optimise quality of life

Compensatory Approach:

Adaptation of activity, introducing equipment, exploring the role of service

Educative Approach:

Energy conservation, techniques, pacing of activities

Cognitive Behaviour Approach:

Health Behaviours

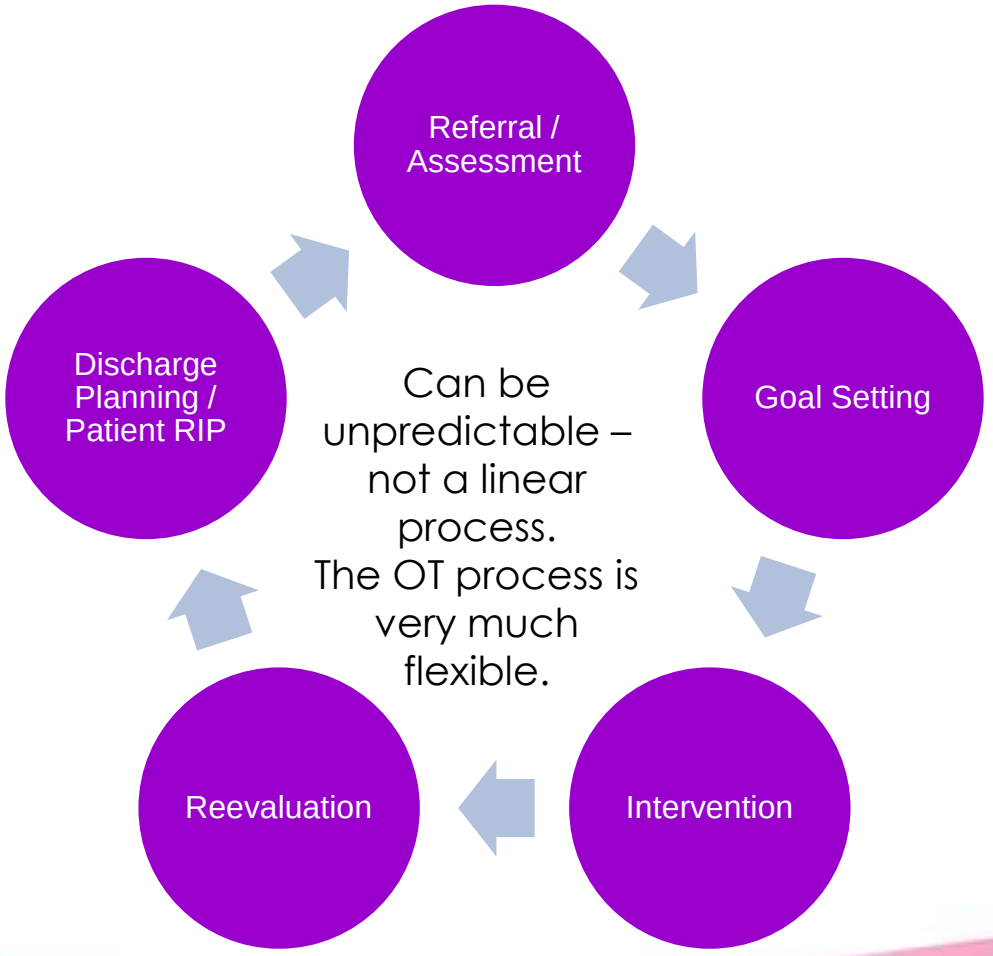
Biomechanical Approach:

Graded programme of activities

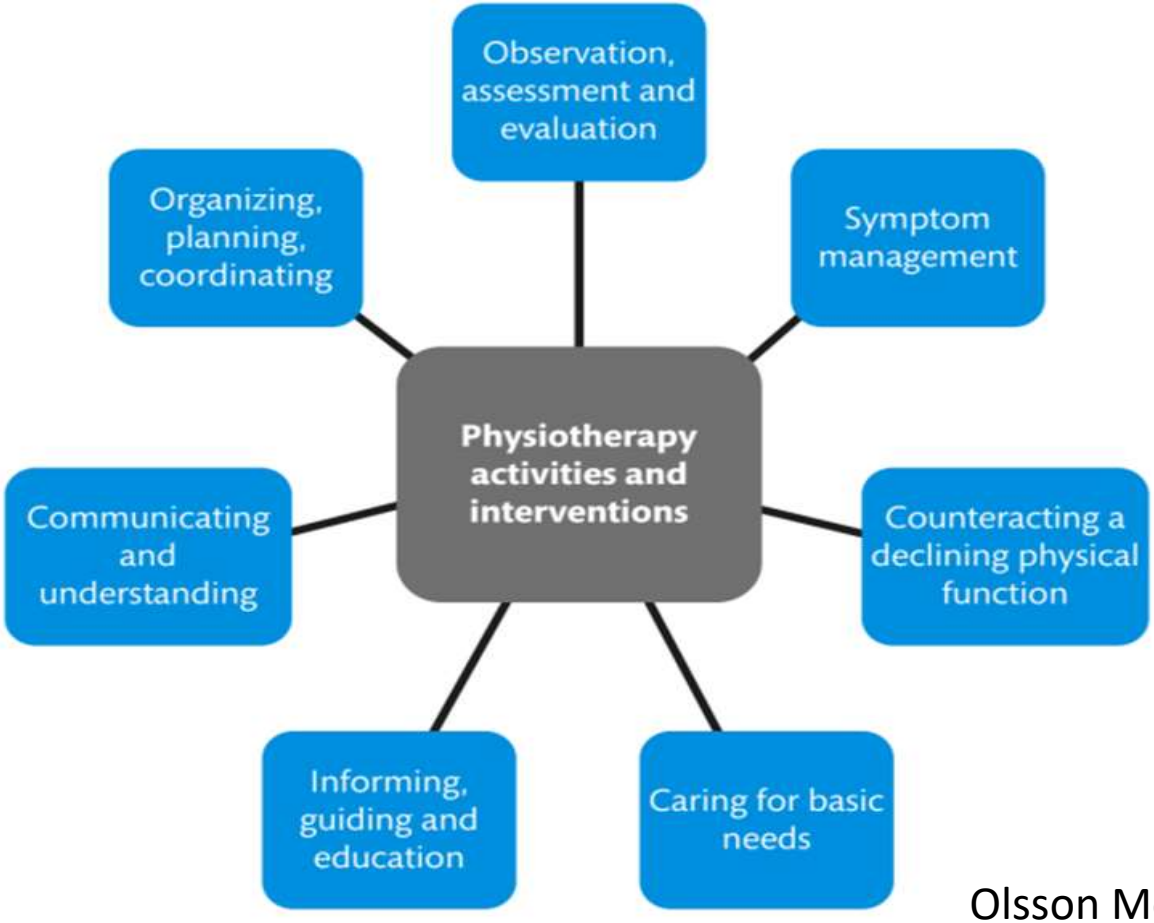
OT Assessment and Intervention

- Functional assessment and intervention
- Seating and pressure care assessment
- Assistive technology
- Equipment
- Home environment assessment
- Cognition
- Symptom assessment and management
  - Breathlessness
  - Fatigue
  - Anxiety
- Exploring leisure occupations to enhance quality of life

Occupational Therapy Process



Role of Physiotherapy



Olsson Moller *et al.*, 2018

The aim is to optimise function and wellbeing and enable patients to live as independently and fully as possible.

The approach empowers people to adapt to their new state of being with dignity and provides an active support system to help them anticipate and cope constructively with losses through deteriorating health.

(Tiberini and Richardson, 2015)

Common symptoms we treat

- Pain
- Fatigue
- Breathlessness
- Reduced mobility
- Lymphoedema
- Deconditioning
- Balance issues
- Reduced ROM
- Soft tissue issues
- Reduced confidence
- Muscle weakness
- Anxiety
- Altered tone

Reduced mobility & balance

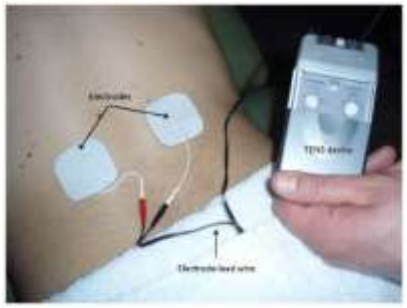
Muscle weakness, deconditioning, reduced ROM

Lymphoedema

- Compression
  - bandaging
  - garments
- Exercise
- Skin care
- Manual Lymphatic Drainage

Pain Management & physio

- Passive movements
- Heat
- Massage
- TENS
- Acupuncture
- Positioning
- Education
- Exercise
- Aids



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Breathlessness Management

- Education- Breathing, Thinking, Functioning Approach
- Fan therapy
- Positioning
- Breathing techniques
- Relaxation techniques
- Walking aids
- Individualised exercise programme
- Airway clearance techniques
- 5 P’s
- Energy conservation
- Oxygen therapy

Fatigue Management

Condition	Prevalence
Cancer	32-90%
COPD	68-80%
Motor neurone	44%

- Individualised exercise programmes
- Energy conservation
- Mobility advice and equipment
- Relaxation techniques

Palliative Rehabilitation

Michelle Coleman

Rehabilitative Palliative Care

- Optimise function and wellbeing
- To enable people to live as independently as possible
- Within the limitations of advancing illness

Specialist Palliative Rehabilitation

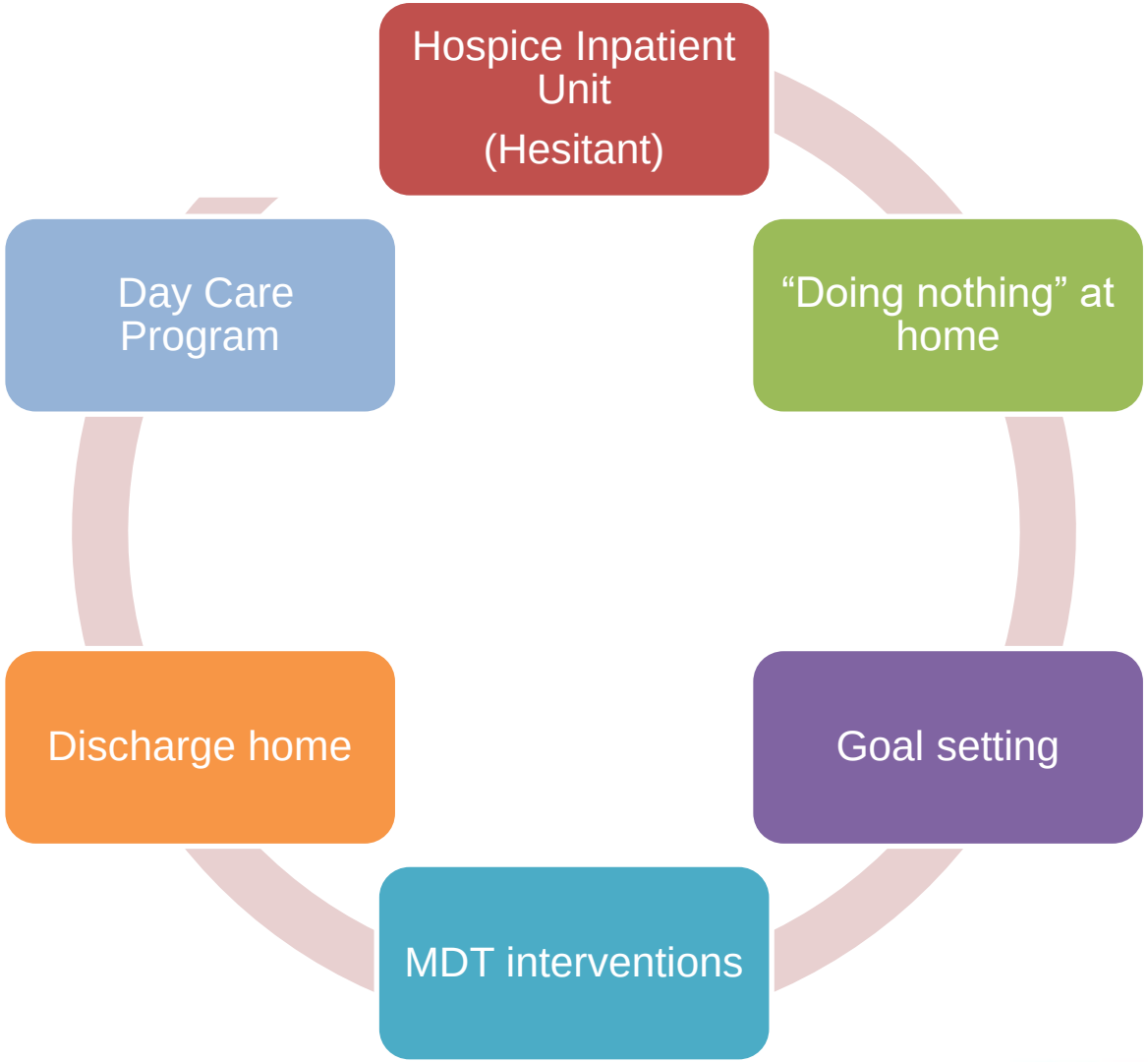
Case Study

- Female in late 50’s
- Acute hospital admission post small bowel obstruction
- Endometrial CA with Metastases.
- Lived in a small bungalow with her partner
- Functionally - mobilising with 4ww and supervision and assisx1 with PADL.

Hospice Inpatient Unit
(Hesitant)
“Doing nothing” at home
Goal setting

Goal setting

- Medical and nursing
- Patient's main goal – "to be useful" at home

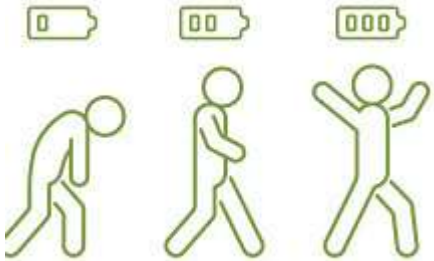

Hospice Inpatient Unit
(Hesitant)
“Doing nothing” at home
Goal setting
MDT interventions
Discharge home
Day Care Program

Day Care

Returned home and re-established routines

New goals identified

- OT - fatigue management
- Physio - improving mobility and pelvic floor/core strength

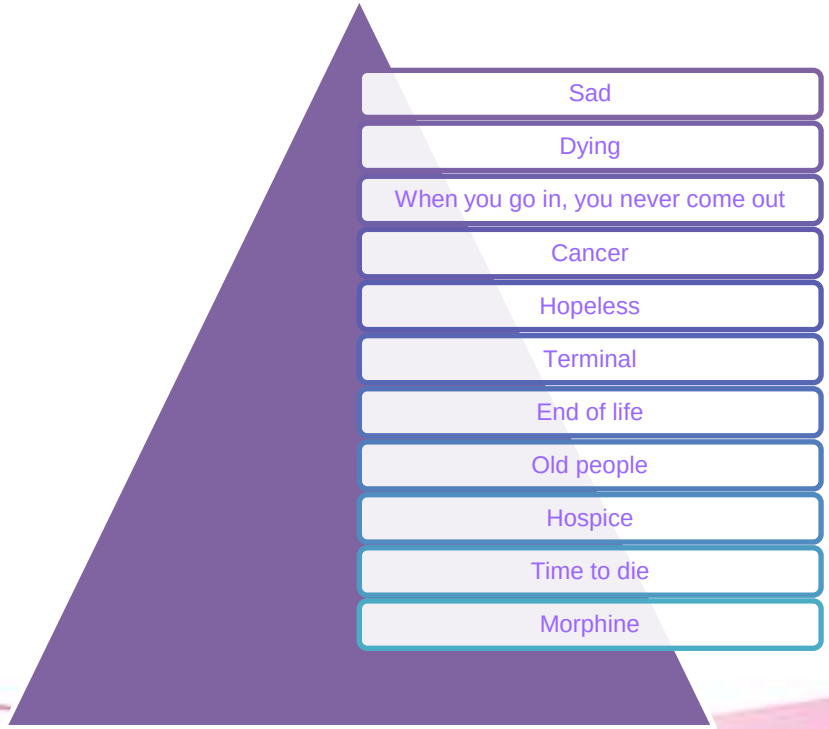


Palliative care myths!

Joan Boult

De-bunking myths

- What is Hospice/Palliative Care?
- In 3 words:
- Results from people with no connection to Palliative care:



What it really is:

- A specialist service providing holistic, individualised multidisciplinary care for people with life limiting illness, it encompasses physical, psychological and spiritual care and supports both patient and family/carers.
- Patients of all ages with a wide variety of serious, complex disease including cancer, respiratory, psychological and neurological.

What it really is:

- Consultant lead. Medical team, Nursing and HCA.
- Physio, OT, MSW, Aromatherapy, Art Therapy, Music Therapy, Pastoral Care, plus input from Speech and Language Therapy, Dietician, Chiropody.
- Care settings include: IPU, Day-Care, Home and OPD clinics eg. Fatigue, Breathlessness, Wellness...
- Admissions to IPU can be for Symptom Control, Respite, Crisis, EOL.
- The aim is to optimise Quality of Life and mitigate suffering by early intervention where possible and to provide a supportive, trusted network of care around the patient and family, that continues throughout disease and afterwards into bereavement.

Palliative Care: the real picture

- 3 words results from people of all disciplines incl. volunteers, working in Palliative care:

Also cited:

Attention to detail
Teamwork (MDT)
Life affirming
Enabling
Engagement
Living
Respect
Kindness
Meaning
Journeying
Flexibility
Listening
Hope
Relief/calmness
Home

What I would add:

- Essential, Challenging, Rewarding
- It's a cheerful environment
- It is very welcoming and friendly
- It engenders team spirit
- There is a lot of laughter
- There is hope
- There is a focus on living well every day
- There is a combined effort to try our very best every day for every patient, to listen to their needs and choices and to try and help them achieve their goals.

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Staff Grade Rotation in Specialist Palliative Care

Julie Healy- Staff Grade Occupational Therapist in Our Lady's Hospice and Care Services.

Why did I choose to work here?

- Completed third year student placement in palliative care. This was between the sites of Blackrock and Harold's Cross.
- Placement allowed for exposure to the area & sparked my interest in working here.
- Provided opportunity to see specialist palliative care in different settings and how different therapists work within each setting.
- Access to a full MDT and for understanding of each person's role e.g. PT, SLT, complementary therapy, chaplaincy, psychology, nursing, social work, and medical team.
- Recognised the need to develop my communication skills as a new grad OT-daily handovers & twice weekly MDTs.

Misconceptions About Palliative Care

- Everyone who is admitted to the PCU are coming in for end of life care- 1/3 of those admitted are discharged home. Some are admitted also for symptom control.
- Our job is always 'doom and gloom'.
- Palliative care only addresses comfort measures.
- Palliative care is the same as 'hospice'. Other rotations on site are not in palliative care.

Rotational Post

- Previous rotation was in an older adult rehabilitation unit for 9 months
- Variation in skill set exposure between the two units
- Staff grade rotations within the hospice include 1) Community Rehabilitation Unit, 2) Specialist Palliative Care, 3) Rheumatology and Musculoskeletal Disease Unit
- As a new grad occupational therapist, these rotations have allowed for in depth learning and incorporation of the OT process.

Skill set development opportunities

- Seating, e.g., high spec seating, powered mobility
- Pressure care management
- Discharge planning & home review planning
- Symptom management e.g., fatigue, breathlessness, pain & anxiety.
- Assistive technology e.g. call bells, access to communication devices, orientation devices.
- Communication and team working skills. Daily handover & twice weekly MDT, family meetings.

Why work in Palliative Care?

- Transferable skills and occupation focused interventions.
- Longer rotation (9 months), allows for service development pieces and enhanced learning in areas of interest.
- Access to resources and knowledge- clinical specialists, senior OTs, supervision opportunities for CPD.
- Value of volunteers in running of OT service e.g., facilitation of hours out, home visits, afternoon tea and transport of equipment.
- Expectations v reality: core principles of occupational therapy are addressed.
- Our knowledge as OTs in the therapeutic use of occupation is invaluable in the specialist palliative care setting.

Community Palliative Care

Siobhan Kinsella

A little bit about me….

- I trained as an OT in the University of Salford Manchester and qualified in 2004.
- I had little experience in Palliative Care when I qualified .
- As a Staff Grade, I worked on a rotational basis in Orthopaedics, Care of the Elderly, Rheumatology, Oncology &Palliative Care and Rehab.
- In 2009 I joined South Tipperary Community Specialist Palliative Care Team as a Senior OT.
- I work as part of the team which consists of a Palliative Care Consultant, Clinical Nurse Specialists, RGN & admin support.
- I see patients with a malignant diagnosis that have been referred to the Team (all ages - Paediatrics, Adults, Older Adults).

So how does it work?

- Referrals will usually come via the MDT meeting, Clinical Nurse Specialists on the team, PHN's, RGN's or other OT's (if it involves a hospital discharge).
- Not all Palliative Care referrals are urgent! I prioritise them according to need **however** I also work closely with my colleagues on the team who can give me a much better sense of the situation. A referral that is a P1 today might not be relevant tomorrow.
- More often than not, I am not involved when the patient is in a terminal phase - "I've done my bit by facilitating the patient's wish to remain at home"

Although Palliative Care Services need to be efficient and provided in a timely manner, the approach is often at a slower pace…. What do I mean by this?

Palliative Care Approach

- I will liaise with the referrer and relevant team members and will organise a home visit if still indicated.
- Equipment needs will be identified but the patient may not be at a point where the OT can have a discussion with them about this.
- It can be difficult to let strangers into your home….you learn to “read the room”.
- There’s still hope! Not every patient that is referred to Palliative Care is close to end of life. Many patients are still on treatment be it not curative.
- Whilst all homes may have sadness there’s still room for smiling, laughing and joking if appropriate.
- The patient may go into a Hospice setting for a short time. Here, they are introduced to the MDT and can be referred onto Community Services if required.

What is my Role?

- Equipment Provision
- Fatigue management
- Energy Conservation
- Goal setting
- Breathlessness Management
- Support
- Keeping it simple!
- “Control the controllable”
- Discharge and re-open if required.

The Pro's to working in the Community….

- The views when driving!
- The flexibility.
- The time to problem solve and reflect.
- No home is the same!
- Unpredictable at times but it keeps me on my toes!
- Although sad at times it can be incredibly rewarding.
- I'm always learning!

What does Community Palliative Care mean to me?

- To me, Community Palliative Care is about supporting somebody through what has already been a really difficult journey.
- Giving patients and families coping strategies.
- Empowering families and facilitating the patient's wish to remain at home for end of life care.
- Supporting them (as a team) in decisions – home vs hospital/care facility/Hospice.
- Everybody has a story to tell and I am privileged enough to hear those stories.

Going full circle….

- When a patient dies, I usually contact the family to offer my condolences.
- Equipment collection needs to be arranged.
- The file is closed – “May John Rest in Peace”.

And finally…..

Advice from a Patient….

This may be a normal day at work for you

But it's a big day in my life.

The look on your face and the tone of your voice

Can change my entire view of the world.

Remember, I am not usually this needy or scared.

I am here because I trust you, help me stay confident.

I may look like I'm out of it

But I can hear your conversations.

I'm not used to being naked around strangers.

Keep that in mind.

I'm impatient because I want to get the heck out of here.

Nothing personal.

I don't speak your language well.

You are going to do what to my what?

I may only be here for four days.

But I'll remember you the rest of my life.

Your patients need your patience.

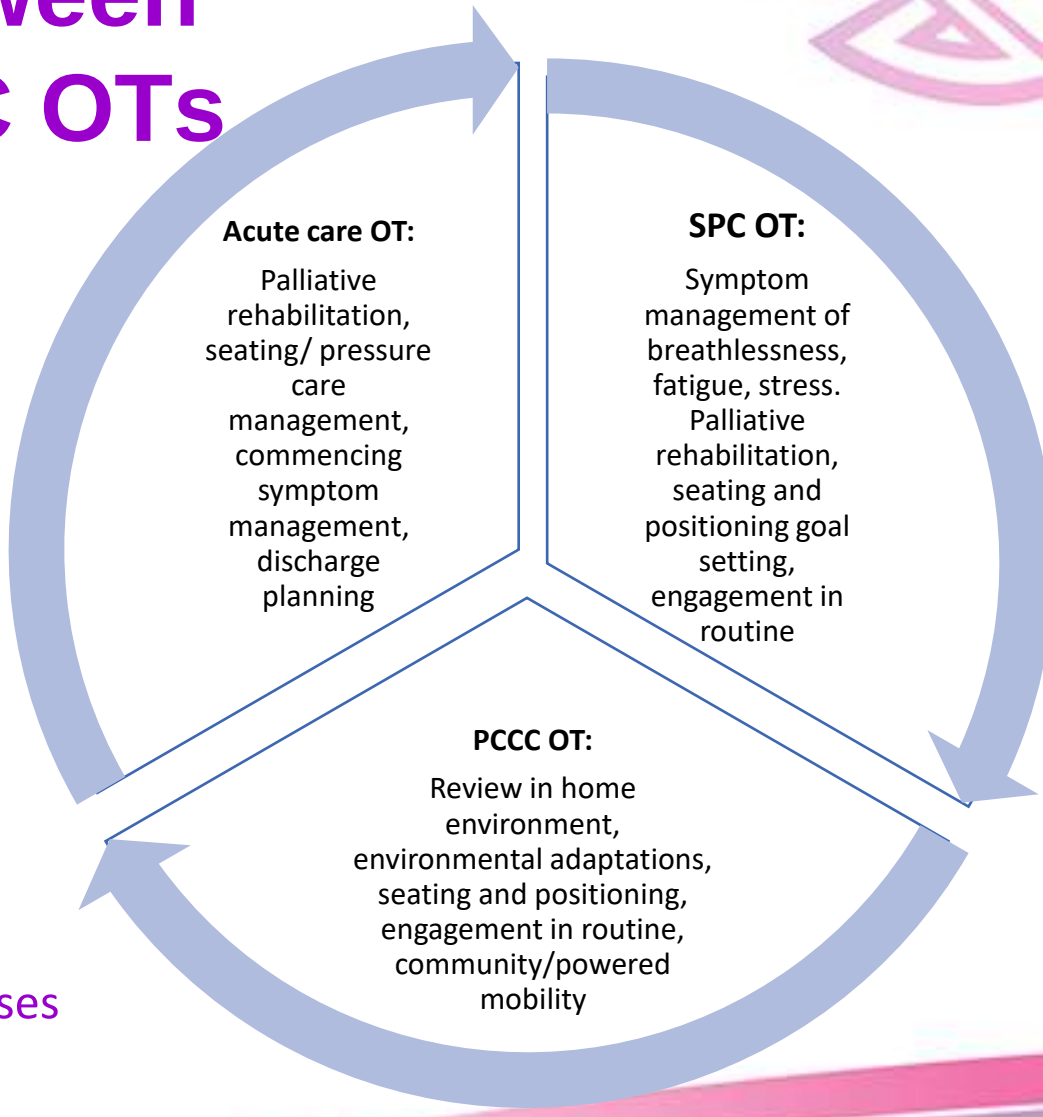
Case Study

Laura Binions

Julie Donohoe

Collaboration between Acute, PCCC, SPC OTs

Collaboration between therapists ensures patients needs are met as they transition from hospital to home



Comprehensive handovers:

- Enhance patient journey
- Promote teamwork
- Support therapists with complex cases

Case Study

- 63 year old man with prostate cancer to bone,
- MMUH patient, also attending OT/PT/CT in SFH and under CPC team. COT involved.
- Attended Empower Programme and 1:1 Physiotherapy appts in OPDS (Spring/Summer)

Nov

New spinal lesion, admitted to hospital - radiotherapy and steroids

→

End Nov

Ref from MMUH OT re: fatigue management to SPC OT

Ref also to COT re: falls risks at home

→

End Dec

Readmission to MMUH with fall at home

→

Transfer to IPU – handover received

?home vs IPU

A Case Study

Megan Roche, Senior Physiotherapist PT034138

Anna Brown Senior Occupational Therapist OT022953

Background Information

Bobby is a 4-year-old boy with leukodystrophy. He was diagnosed at 6 months of age.

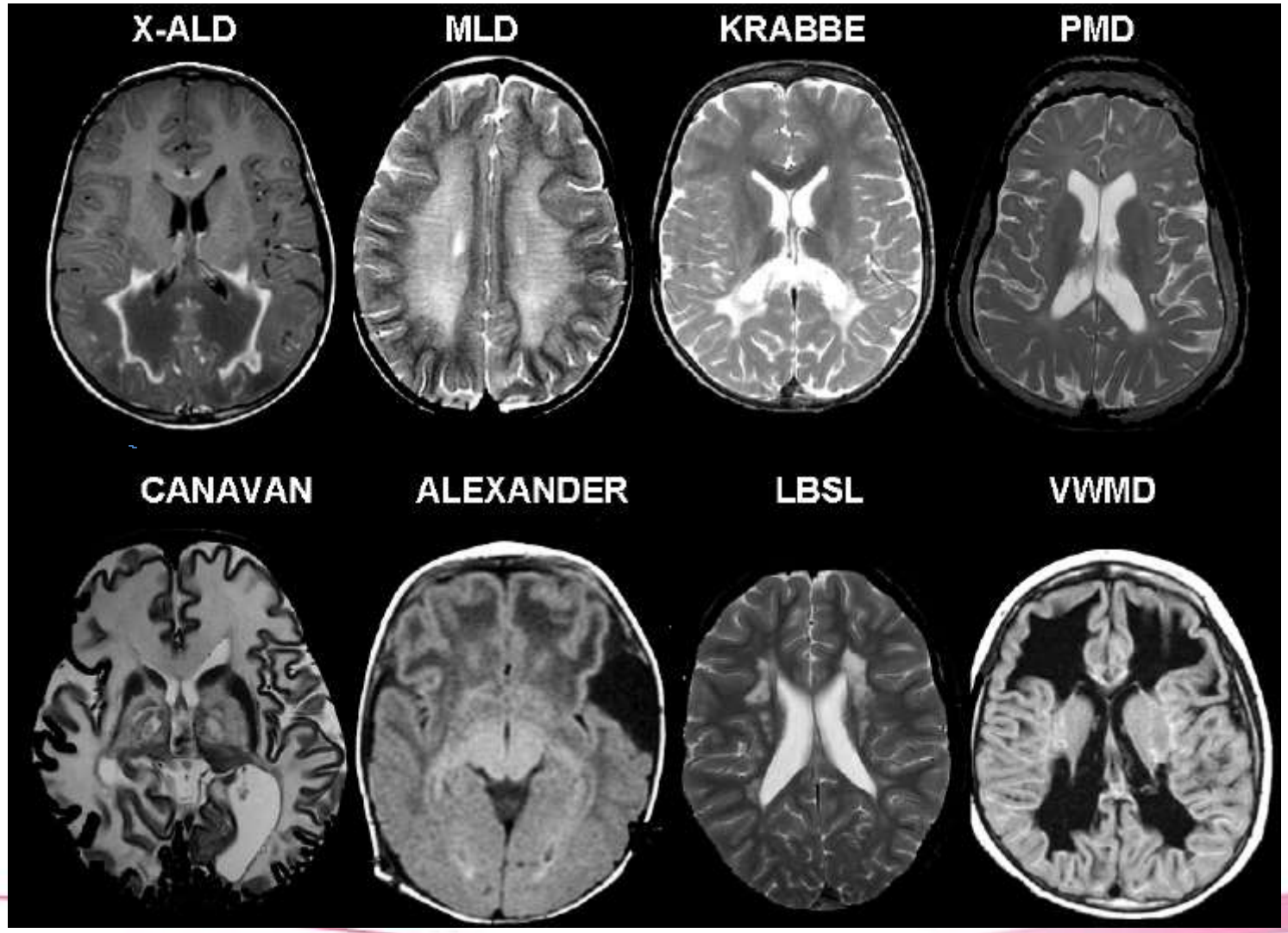
Bobby's symptoms include low tone, clonus, epilepsy, feeding difficulties- he is PEG fed, constipation, gastro-oesophageal reflux, recurrent chest infection, hip dysplasia, scoliosis and osteoporosis.

He has an advanced care plan which states that he is not for ICU or intensive interventions but all reversable conditions should be treated.

Social History: Bobby lives at home, in a two-story house with his parents and his brother and sister. His brother also has additional needs and is linked with his local CDNT (Children's Disability Network Team).

Bobby sleeps in a profiling junior sized bed in the family sitting room. His parent lift him, he has a shower seat and adapted ground floor bathroom, an adapted buggy, activity chair, standing frame and orthotics.

Bobby attends his local preschool for mornings, 3 days a week


X-ALD
MLD
KRABBE
PMD
CANAVAN
ALEXANDER
LBSL
VWMD

The Multidisciplinary Team

1. Children's Disability Network Team (CDNT) including paediatrician
2. Clinical Nurse Coordinator for Children with Life Limiting Conditions (HSE)
3. Community Nursing Team including Jack and Jill
4. Temple Street neurology, palliative care and respiratory teams
5. Adult Hospice Team
6. LLH at home nursing team, Family Support Team and hospice team,
7. Pre-school staff

Bereavement Theories / Grief

- Continuing Bonds Theory- maintaining a relationship with the deceased person (goodgrief.org)
- Anticipatory Grief
- Bereavement literature suggests that families biggest regret is not having opportunity for **Play and Meaningful Interactions** with their child (Tan et al. (2010) Drench, M,E, (2005), Hilllard, R.E. (2001)

- **Relationship building** with the child and family becomes an essential aspect of the work.

Physiotherapy

Paediatric Physiotherapy Palliative Goal: to maximise comfort

- Support CDNT physio to assess the need for postural management equipment
- Support CDNT physio to issue and adjust the child's sleep system and standing frame
- Support the parent to carry out a stretching programme and use orthotics
- Support the parent to carry out a chest physio plan at home
- Provided training to nursing staff to help them carry out a chest clearance and postural management plan for the child
- Education on parent self care / back care

Occupational Therapy

Capture/ validate mile stones:
First meal
Painting etc

Inclusion

Inviting siblings and the child in how the other experiences the world

Adaptation

Age appropriateness

Summary

1. We always work as part of a wider MDT and communication is key to coordinating the care we provide/
2. Bereavement Theories underpin the work we do
3. Rapport and relationship building is fundamental to the work

Transferable Skills

Jean Ryan | Senior Physiotherapist |Milford Care Centre

Julie Donohoe | Senior OT | St. Francis Hospice

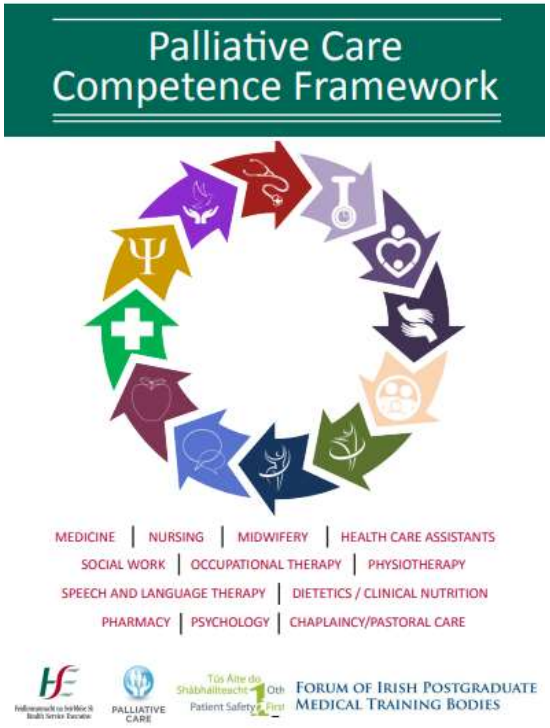
Using your Transferable Skills

- Integral to profession
- Taken from one job to another
- Past employment
- Work experience
- Voluntary work

Clinical	Organization
Communication	Leadership
IT skills	Problem-solving

What Skills Can you Gain?

Conditions & symptoms	Comprehensive assessment & management	Person-centred practice
Quality of life	Communication	MDT
Evidence based practice	Opportunities for developing group facilitation skills	CPD



Any Questions?

Panellists

Orlaith Martin

Ciarán Haberlin

Julie Donohoe

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Thank you

www.thepalliativehub.com

www.aiihpc.org

Further information: