



Institiúid Ailse Choláiste
na Tríonóide/San Séamas

Trinity St James's
Cancer Institute



The challenges Faced by Persons with an Intellectual Disability throughout a Cancer Journey

Laura Sweeney

Medical Oncology ANP

St James Hospital

Summary

People with **Intellectual Disabilities** experience **additional challenges** when facing a cancer journey.

In order to **improve experience and outcomes**, healthcare professionals must address these shortcomings to **build a more inclusive service**.

Intellectual Disability (ID)

World Health Organisation

The significantly reduced ability to **understand new or complex information** and to learn and apply new skills.

This results in a **reduced ability to cope independently** (impaired social functioning), and begins before adulthood, with a lasting effect on development.

American Association of Intellectual and Developmental Disabilities

An individual is said to have an intellectual disability if he/she meets the following criteria:

1. IQ is below 70-75
2. There are significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care)
3. The condition manifests itself before the age of 18 (AAIDD)

ID and Cancer

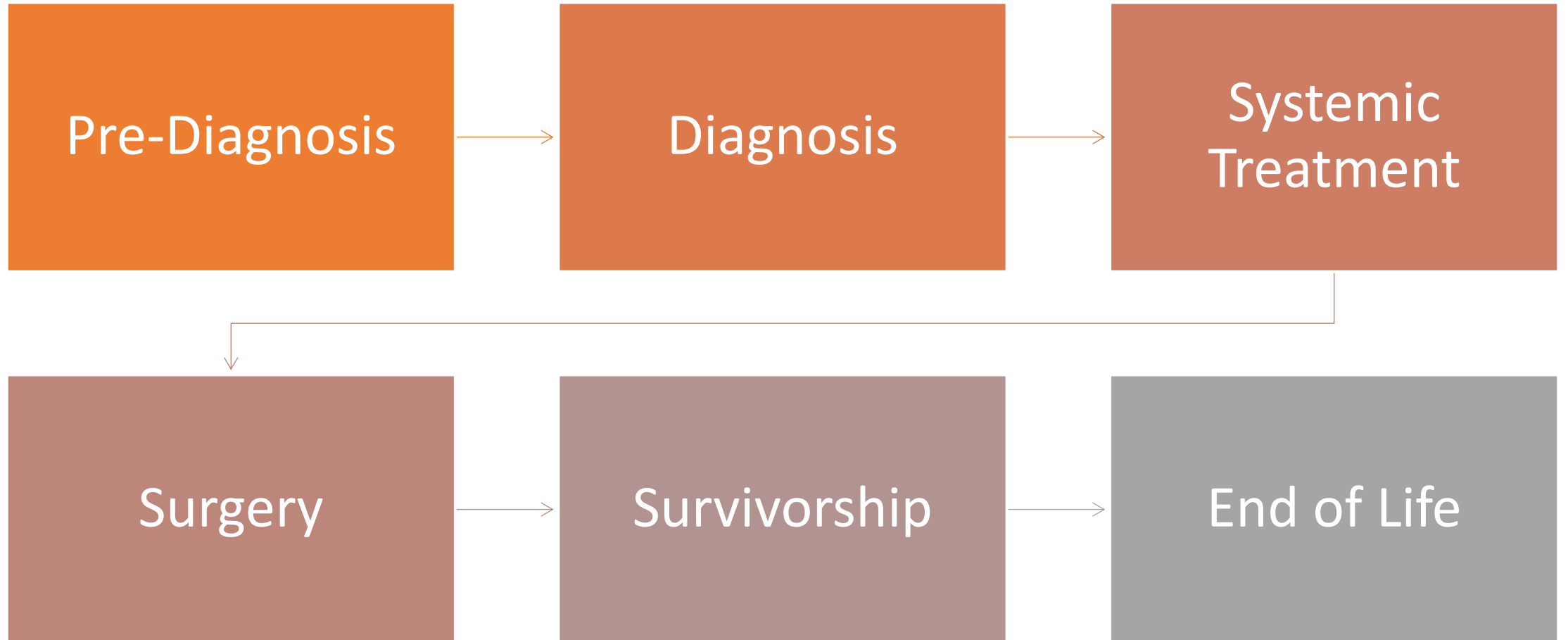
People with ID:

- Have a higher risk of developing cancer
- Are more likely to be diagnosed at a later stage
- Experience poorer outcomes
- Have a higher risk of mortality

Cancer is the second leading cause of death in Ireland for people with IDs who live in residential care

Instance of Cancer related death is recorded 1.5 more often for patients with IDs

Cancer Journey



Obstacles

- Reduced access to care
- Barriers to screening
- Communication challenges
- Impact of comorbidities
- Need for specialised care
- Research gap

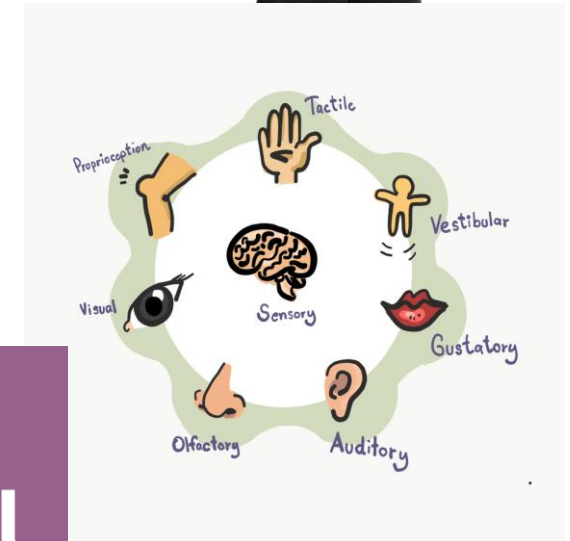
Established Initiatives

- Easy Reads
- HSE Health Passport
- Accessible end of life tool
- My future care road map
- Sensory solutions
 - Sensory/quiet rooms in high activity environments
 - Sensory box's
- Additional Needs Working Group

**My Future Care
Road Map**



**Accessible
Planning Tool**



What do we need to do?

- Patient focused and individualised care
- Inclusion in Patient Representative Groups (PRGs)
- Additional needs working groups - nationwide
- Education and communication regarding screening programs
- Research > The CANDID 2 Study

Case Study - Tommy

Patient	46 Year old man with Downs Syndrome	Treatment	4 doses given 2 weeks apart
Diagnosis	Stage 3 gastric adenocarcinoma	Surgery	Gastrectomy
Presentation	Fatigue, anaemia, abdominal pain Symptoms increasing in severity over 6 months	Post Operative Chemotherapy	Tolerated 2 doses
Investigation	OGD, Laparoscopy, PET scan, Bloods	Survivorship	ANP follow up for 5 years
MDT	Surgically resectable – standard of care > perioperative chemotherapy		

Case Study - Adjustments

Treatment	Ethical Considerations	Collaborative Care
<ul style="list-style-type: none">• Communication• Support System• Emotional needs	<ul style="list-style-type: none">• Competency assessment• Best interest• Support system	<ul style="list-style-type: none">• Patient• Healthcare Professional• Social Workers• Family & caregiver



Institiúid Ailse Choláiste
na Tríonóide/San Séamas

Trinity St James's
Cancer Institute

Thank You!