



Occupational Therapy and Physiotherapy at an Irish ALS Centre: An Audit to Review Care Links with Community Care Services

Allied Health Professionals Forum, Berlin, 7th December 2009

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International Context to ALS Services

- AAN, ALS Practice Parameters Task Force (Miller et al, 1999); did not specify mix of health professionals



- Borasio et al (2001); European survey of ALS care: discrepancy in MDT care



International Context to ALS Services

- EFNS Task Force (Andersen et al, 2005, 2007): Guidelines for diagnosing and clinical care of ALS patients
 - Secondary / tertiary centre
 - Clinical lead by a named neurologist
 - Continuous throughout the course of ALS
 - Co-ordination between tertiary, secondary & primary care
 - Frequent clinical review
 - Mix of skilled health care professionals

International Context to ALS Services

- Phukan & Hardiman (2009) & Radunovic et al (2007) describe optimal care in ALS
- Describing structure and benefits of ALS centres in ALS care
 - Corr et al (1998)
 - Han et al (2003)
 - Mayadev et al (2008)

Benefits of Multidisciplinary Care

- Traynor et al (2003): prospective population based study; better outcome in prognosis for bulbar onset
- Van den Berg et al (2005): higher QoL in psychological & social domains and better access to aids & appliances
- Van der Steen et al (2009): negligible difference between costs of MDT versus general care
- Chio et al (2006): prospective population based study; MDT clinic - independent positive factor in survival (including spinal onset)

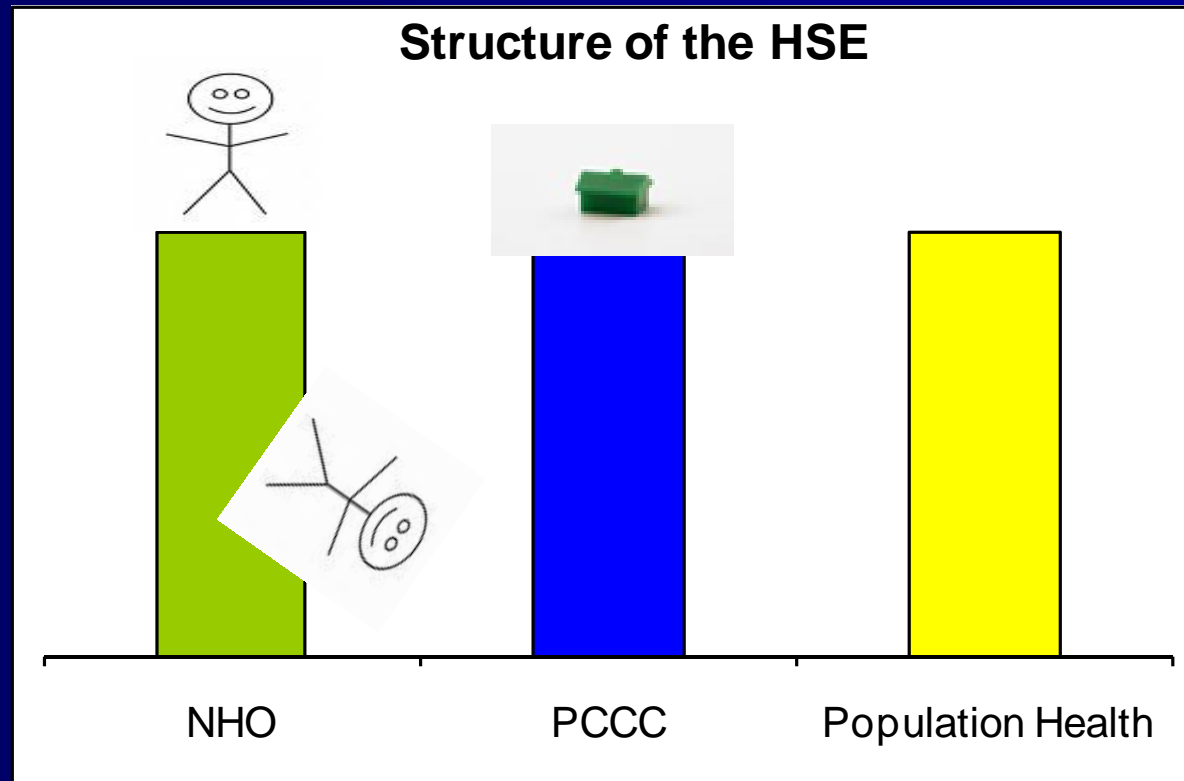
Irish Neurology services



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Irish Health Care Services

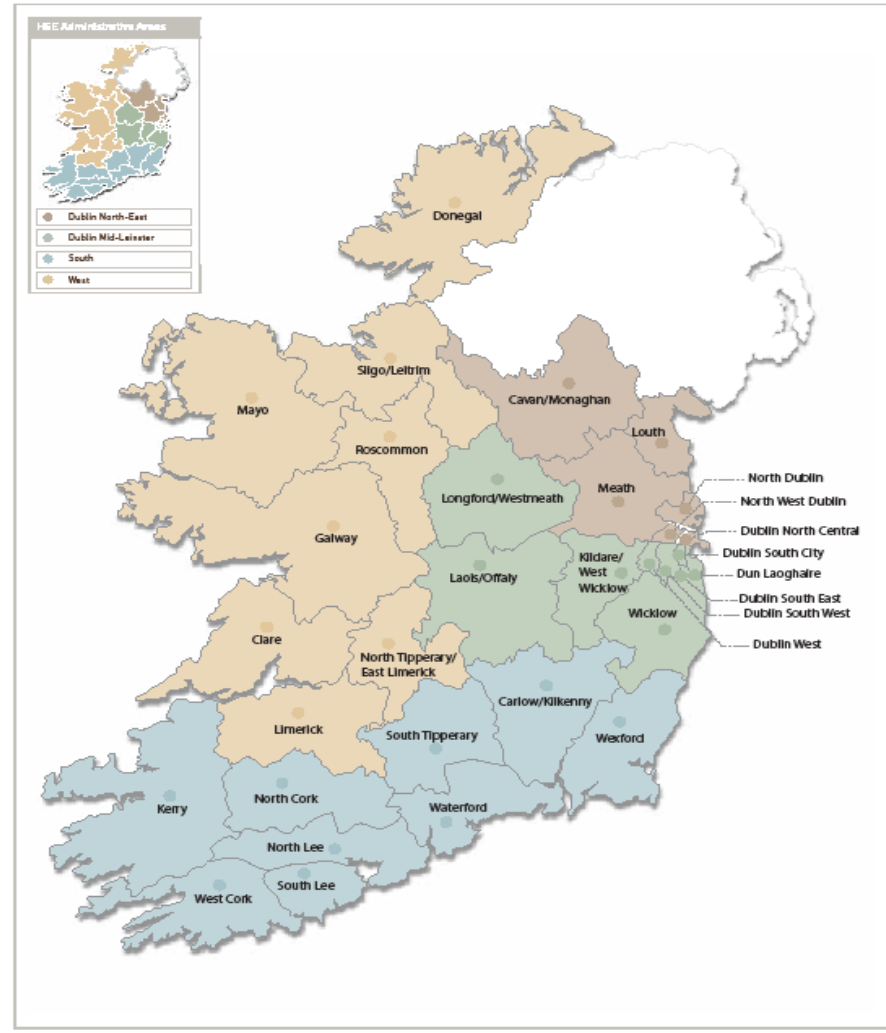
Health Service Executive (HSE)



HSE & Primary care; Local Health Offices

Location of HSE's Four administrative Areas and 32 Local Health Offices

Figure 2: HSE's Four Administrative Areas and 32 Local Health Offices



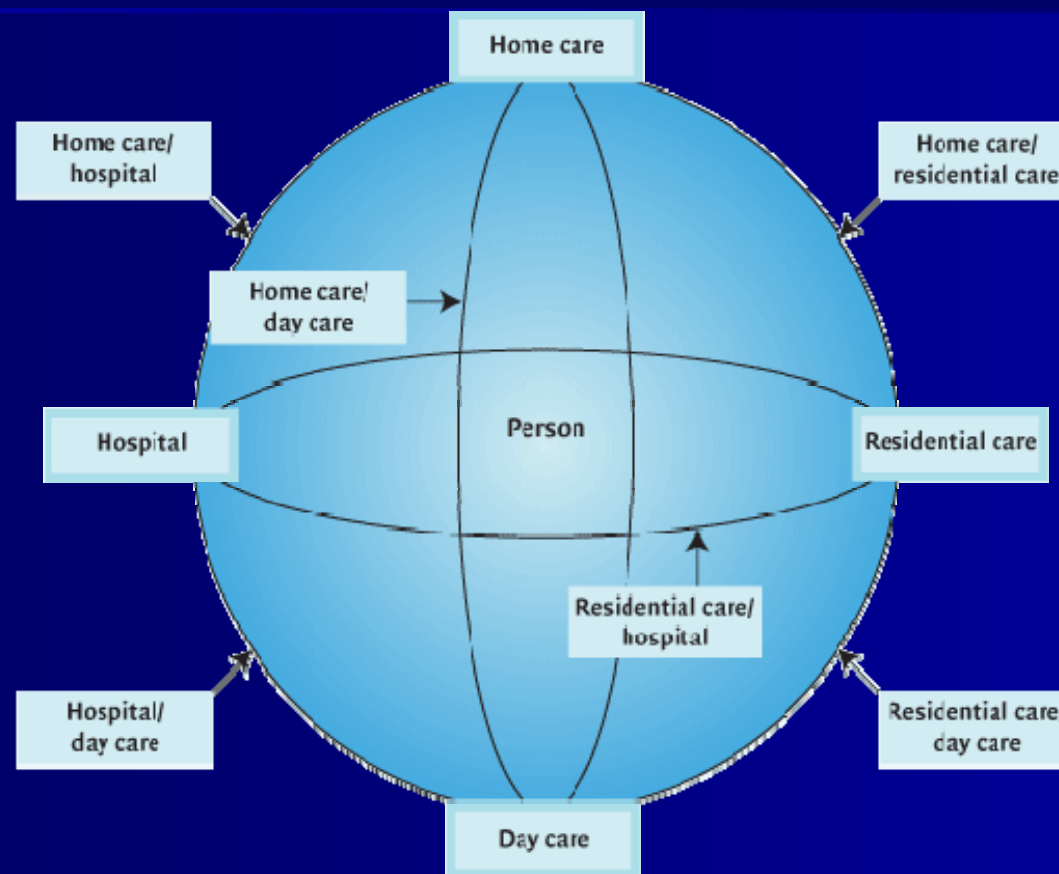
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Irish ALS services



- Neurological Alliance of Ireland (2000-2002): Set out specifics on minimum standards of care in neurology
- Neurology Steering Group (2007): problems accessing neurology services and MDT care
 - Fragmented & poor infrastructure
 - Under-resourced
 - Primary care means tested
 - Benefits of private health care limited for access to co-ordinated MDT hospital and primary care

Irish ALS services

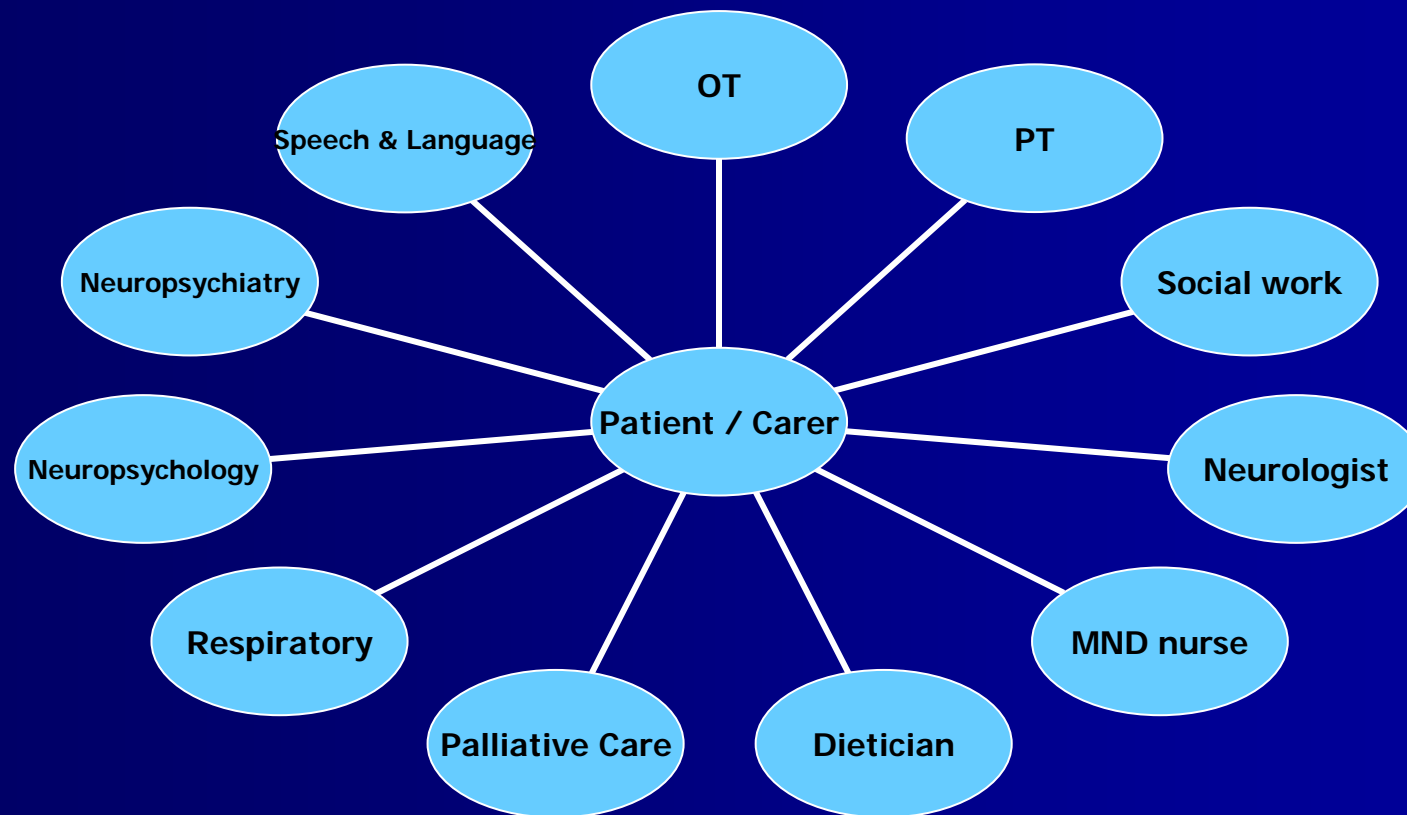


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Beaumont Hospital Multidisciplinary ALS Clinic

- Established 1994
- Approximately two thirds of Irish ALS population
- Regional hospital for North Dublin & tertiary neurological centre
- Multidisciplinary care & research
- Neurologist, MND nurse specialist, physiotherapy, occupational therapy, speech & language therapy, dietetics, social work, respiratory, neuropsychology, neuropsychiatry, palliative care

Beaumont Multidisciplinary ALS Care



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Objectives

- Audit services and standards of care provided by OT and PT at Beaumont Hospital ALS centre
- Evaluate correspondence between hospital and community / primary care services (PCCC)

Description

- Retrospective audit from 1st Jan – 30th April 2009
- Inpatients and outpatients
- PT and OT benchmarked against practice guidelines
- Correspondence between hospital and community services reviewed

Outcomes

OT/PT	Patients	Known to PCCC prior to Beaumont visit	Correspondence from PCCC prior to Beaumont visit	Correspondence to PCCC from Beaumont	Correspondence from PCCC post Beaumont referral
OT	49	37%	0%	98%	57%
PT	42	33%	0%	81%	8%

Outcomes

- OT and PT at Beaumont Hospital met guidelines re: access to specialised OT and PT services in a tertiary care setting
- Communication between hospital and PCCC fragmented
- Difficulty accessing community OT and PT services
- Highlights problems in OT & PT service delivery in Ireland

Outcomes

- OT and PT identified;
- Uncertainty about respective services
- Services in general and roles of professionals in community care



Recommendation no. 1

Develop **'Patient Information Passport'**

- Patient
- Hospital health care professionals
- Community / primary care health care professionals

Functions

- Record health care professional involvement on each intervention
- Explain role of each health care professional
- Record equipment
- Provide resource information



imndrf
Irish Motor Neurone Disease Research Foundation

Motor Neuron Disease Patient Passport

To the Healthcare Professional

This MND patient management passport aims to help patients keep track of the many healthcare professionals that they may encounter.

It will also assist in improving communication between healthcare professionals and between the hospital and community based teams.

It contains links to resources on management of MND that may be helpful to healthcare professionals.

Please complete your contact details and initial and date on each contact.

This passport is not a medical record and any specific assessment or treatment information should not be recorded here.

Beaumont Hospital Contact Details

Contents

Clinic Secretary Margaret Young Tel: (01) 809 2174 Email: margaretyoung@beaumont.ie	Medical Team/GP	6
	IMND Clinical Nurse Specialist, IMNDA and PHN	8
	Physiotherapy	10
MND Research Office Catherine Lynch Tel: (01) 809 3874 Email: clynch@rsci.ie	Occupational Therapy	14
	Speech and Language Therapy	18
Neurology Registrar on Call: (01) 809 3000	Dietetics	22
St.Brighids Neurology Ward: (01) 809 2425	Social Work	26
	Palliative Care Team	29
	Equipment supplied	30
	Useful Resources	32

Aims

- Facilitate patient participation
- Promote collective responsibility to services
- Facilitate better understanding for service users
- Improve care links and accountability between hospital and community services
- Use as a template for other diagnostic groups to promote MDT care

Recommendation no.2

2. Research study

How service users with ALS understand health care services

Studies which explored ALS service user experiences with respect to the services they access;

- Biesecker et al (1988)
- Brown (2003)
- Brown et al (2005)
- Foley et al (2007)
- Hughes et al (2005)
- Kattilakoski (2004)
- Kristjanson et al (2005, 2006)
- McCabe et al (2006)
- van Teijlingen et al (2001)

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