

The background of the slide is decorated with several overlapping circles. There are three solid light purple circles and two hollow light purple circles, arranged in a pattern that partially overlaps the text.

Patient Organisations and the Concept of Self Management in Ireland: The Forefront of Innovation

European Month of the Brain



www.nai.ie

The Neurological Alliance of Ireland

- Umbrella of 30 member organisations
- Not for profit service providers and representative organisations
- Recognised as a key voice in shaping the response to neurological conditions in Ireland
 - promoting awareness
 - advocating for change
 - providing an active responsive network to meet the needs of its member organisations

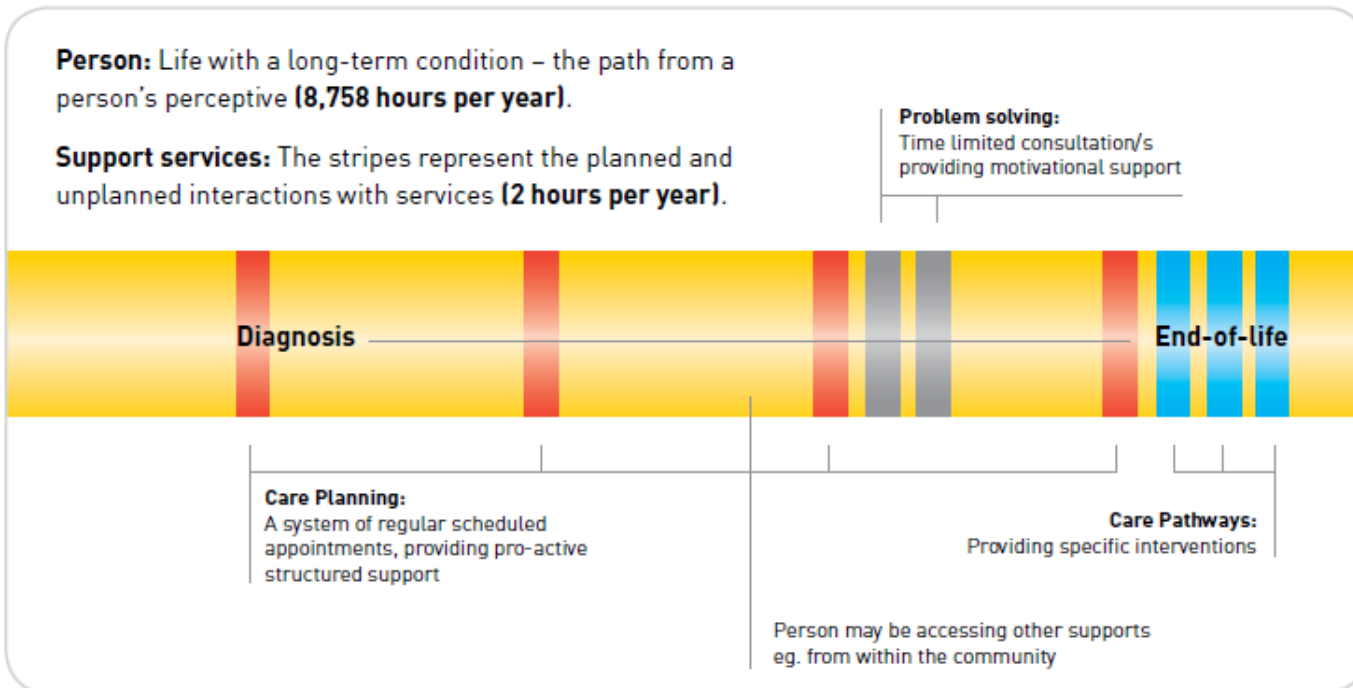


Self Management Support :

The term *self-management support* describes the work of carers, health professionals, community organisations and systems in supporting people with chronic conditions to self-manage

Living with Chronic Illness

Diagram 2: Who's condition is it anyway?



Changing views of healthcare





Self Management in Ireland

- Traditional approaches
- Specialist and interventionist
- Isolated disease-specific pockets of development
- Not for profits leading the way
- National Framework


Not for Profits: Uniquely positioned

- Ireland strongly reliant on not for profit providers of health and social care services
- Holistic perspective
- Strong links with individual over time
- Experienced in individualised goal setting
- Family support
- Peer to peer support
- Bridge between services

The NAI and Self Management

- Developing the Framework
- Exploring the Concept of Self Management with Member Organisations
- Joint Project with DFI to
 - Pilot Capacity Building
 - Share expertise
 - Promote Recognition of Not for Profit sector in supporting self management

Self Management in Practice




nai NEUROLOGICAL ALLIANCE
of IRELAND

**As part of its month long series of events
to mark European Month of the Brain**

**The Neurological Alliance of Ireland and
its members welcome you to:**


**NEUROLOGICAL WELLNESS DAY
CORK**

Over 700,000 people in Ireland are living with a neurological condition.
Find out more about Brain Month and
the Neurological Alliance of Ireland at www.nai.ie



Open your mind!

European Month of the Brain
May 2013



Coleraine House, Coleraine Street, Dublin 7
Phone 01 8724120 Fax 01 8732883
email naireland@eir.com.net www.nai.ie

Neurological Alliance of Ireland

Self management in Ireland: Issues and challenges

- Ensuring access
- Agreeing standards
- Broader definition
- Role of not for profits: Scottish example
- Engaging health professionals
- Leadership and direction
- Integration into existing and future planning

Example 1: My Epilepsy Toolkit:

Epilepsy Ireland

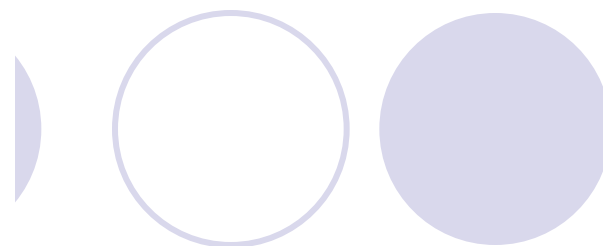
- Two parts:
 - Epilepsy Journal
 - Seizure diary
 - Medications
 - Medical team
 - Appointments
 - Living well with Epilepsy
 - Psychosocial
 - Lifestyle issues
 - FAQs

Example 2: MS Society South East

- Six session Self Management Programme
- Developed for MS but applicable to other chronic illness especially progressive neurological conditions
 - Session 1: a tool to enjoy the whole of my health
 - Session 2: Choosing self management techniques
 - Session 3: Being Active
 - Session 4: Keeping Calm
 - Session 5: Eating Well
 - Session 6: Utilising Resources

Key stages where people need support

Key stage	Issues	Impact of self management
Diagnosis	<ul style="list-style-type: none"> • By this point someone's life and ability to manage may already have been seriously affected by symptoms. • People feel challenged about their place in the world and the reality of their situation. 	<ul style="list-style-type: none"> • Helps people come to terms with diagnosis. • Key to helping people reconnect with themselves and others. • Helps people make better decisions about treatment options.
Living for today	<ul style="list-style-type: none"> • People need information and skills to maintain optimum wellbeing. • Serious risk of social exclusion. 	<ul style="list-style-type: none"> • Supports people to navigate an often difficult journey. • Challenges social exclusion by helping build bridges back into society and social roles.
Progression	<ul style="list-style-type: none"> • Cycle of illness and wellbeing arising from fluctuations in condition. • Increasing severity of symptoms. • Struggle to get additional support during flare-ups. • Possible loss of capacity. 	<ul style="list-style-type: none"> • Helps to avoid (or minimise the extent of) flare-ups. • Enables people to recognise early warning signs and react effectively. • Tackles psychological impact of flare-ups or progression. • Supports changing needs.
Transitions	<ul style="list-style-type: none"> • Moving between services, sometimes to different levels/types of support. • Dealing with multiple needs/ conditions and therefore a range of services. • Often a stressful time and this can have serious impact, including on person's condition. 	<ul style="list-style-type: none"> • Supports person to manage transition processes. • Maintains focus on person's needs ensuring services are organised around these. • Provides person with control at a time when this can be undermined.
End of life	<ul style="list-style-type: none"> • Difficult time involving complex challenges. • Death may be premature. • Person may have to cope with symptoms of condition alongside additional challenges of end of life. 	<ul style="list-style-type: none"> • Supports person to meet range of challenges and maintain control. • Addresses broader needs e.g. emotional, family and lifestyle.





Thank you for this opportunity

Website: www.nai.ie

E mail: naiireland@eircom.net