

Trying to Hit a Moving Target: The challenges and opportunities of working with clients with rapidly progressing conditions



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Aims for the session



- To further awareness of Rapidly Progressing Conditions and their impact on all involved
- To understand the challenges associated with this client group in terms of EAT assessment and provision
- To highlight the reasons for trying
- To consider appropriate models of intervention and service provision for this client group
- To consider the future impact of the changing NHS when working with this client group
- To generate peer learning through discussion

What are Rapidly Progressing Conditions?

- Refers to neurodegenerative conditions
- ‘A rapidly progressing condition (RPC) is a long term neurological condition which progresses rapidly to a state of advanced disability and subsequent death. Motor Neurone Disease (MND) is the most common example’ (DOH 2005)
- Can include MND, nvCJD, MSA, aggressive forms of M.S, PSP etc

The Adult CAT Service and RPC

- The EK Adult CAT Service is a multi-disciplinary service that assesses for, and provides clients with, high-tech communication aids and/or alternative computer access.
- Types of service
 - Assessment and provision
 - Consultation
 - Provision only
 - Transition (from CCAT to Adult CAT)
 - Loan Library (long-term as required) and short term loan (up to 1 month)
- Since starting in 2009 we have been involved with:
 - 41 number of clients with MND
 - 8 number of clients with MSA
 - 3 number of clients with PSP
- Currently have 6 number of clients with MND on caseload

Motor Neurone Disease

- 7 people in 100 000 living with MND at any one time
- Characterised by progressive degeneration of motor neurones
- Also known as Lou Gehrigs disease in USA and ALS in USA/ Europe
- Initial presentation is commonly in 2 patterns either limb weakness 75% or speech/swallowing problems 25%
- Average life expectancy is 2 – 5 years from onset of symptoms
- Symptoms depend on type of MND (though these often overlap)
- No cure. Interventions include
 - Medication (Riluzole) believed to extend life 3 -6 months
 - Symptom management
 - Strategies and equipment to aid independence

(MND Association 2010)

Symptoms



- Amyotrophic Lateral Sclerosis (65%) 2 – 5years
 - Weakness and muscle wasting in limbs, spasticity, hyperactive reflexes, emotional lability, Fasciculations, Weight loss
- Progressive Bulbar Palsy (25%) 6 months – 3 years
 - Dysarthria and dysphagia, nasal speech, tongue atrophy and fasciculation, pharyngeal weakness, tongue spasticity, emotional lability
- Progressive Muscular Atrophy (<10%) 5+ years
 - Muscle weakness and wasting, weight loss and fasciculation
- Primary Lateral Sclerosis (approx 2%) – normal lifespan
 - Muscle weakness, stiffness of limbs and increased reflex response
- Other... cramps, saliva control, cognitive change (35%), fronto-temporal dementia (5 – 15%), breathing difficulties

NB: 80% will eventually develop Dysarthria

(MND Association 2007)

Example timeline of disease progression

- Adrian was diagnosed ALS in March 2010, he had experienced symptoms for approx 6 months
- Referred for computer access in April 2010, assessed 2 weeks later
- Presentation timeline:
 - April 2010: independently mobile, floppy arms minimal UL activity), speech 100% intelligible – some slurring noted, intact head control
 - June 2010: Speech slurred, difficulty rising from chair, respiratory issues – using b-pap
 - Sept 2010: Wheelchair dependent, difficult to understand when tired, requires head support
 - Dec 2010: No verbal output (low volume utterances only), no trunk control, lateral head tilt only, admitted to Nursing Home
 - Jan 2011: Passed away.



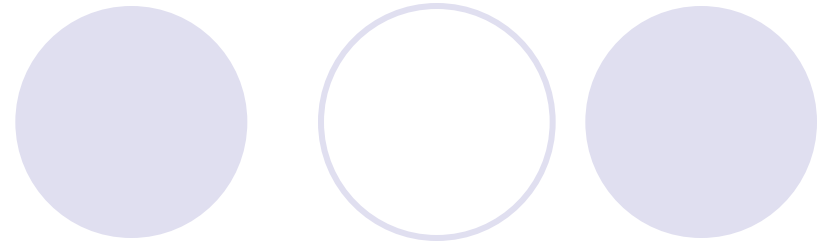
Assistive Technology and RPC

- It is recognised that a successful outcome in AT depends upon:
 - Appropriate match between person and technology (Scherer 2005, Cook and Hussey 2008)
 - Training to enable the individual to achieve communicative competence (Light 2003)
 - Skill acquisition to achieve automaticity (Treviranus 2003)
 - Commitment and support of team (family, carers, health professionals etc)
- The AT assessor faces challenges to achieving a 'successful outcome' when working with clients with RPC

Challenges of working with RPC

- Changing presentation.
 - Tendency towards rapid progression of MND (or any RPC) necessitates regular review and re-assessment, and makes the need for future planning essential.
 - Difficulties predicting rate and type of progression (influenced by symptom management measures)
 - Do you provide for the 'now' or for the likely end stage?
- Adjustment:
 - Rapidity of the progression of the disease allows little time for adjustment. This impacts upon the acceptance of advice and equipment.

More challenges!



- Limited time and resources:
 - Do you and the individual/family/carers have the time and resources to acquire the skills for automaticity and communicative competence?
- Ongoing Support:
 - Support at all stages is needed for all those involved – ‘the doorstep conversation’
 - Need for a multi-disciplinary/multi-service integrated approach
 - Emotional challenge to you!

Why try???

The header is decorated with a row of five circles. The first circle is solid light purple and contains the text 'Why try??'. The second circle is an outline of a light purple circle. The third circle is solid light purple. The fourth circle is an outline of a light purple circle. The fifth circle is solid light purple.

“It’s given me back my life”

“It’s given me my confidence back”

“My daughter could tell me she was engaged and I could show her how happy I was”

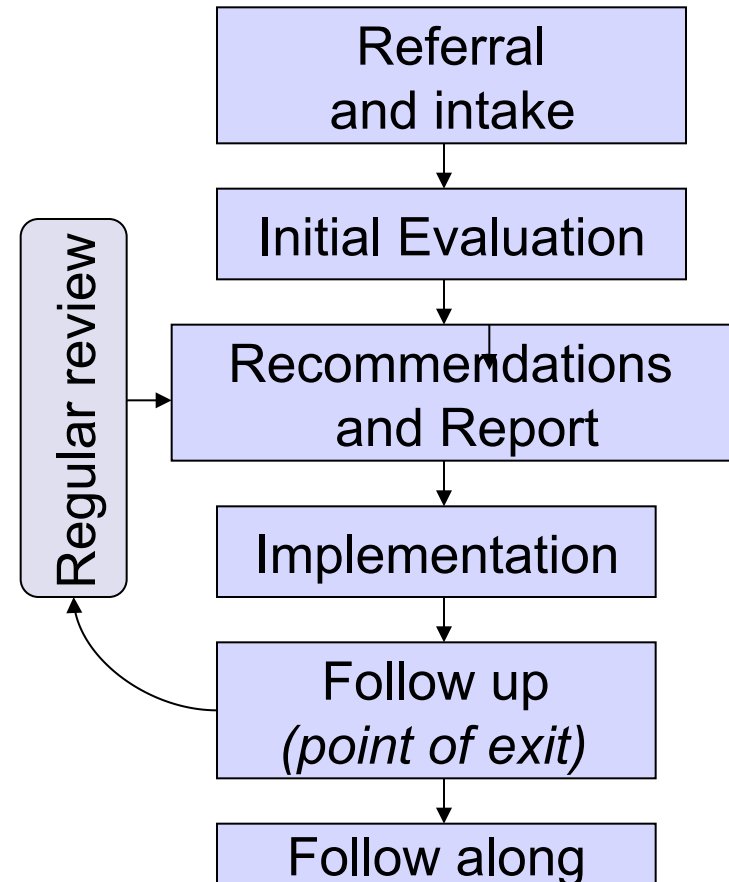
“It’s exciting to see what I will be able to do”

“I can keep working, otherwise I would go stir crazy”

EAT is a enabler at a time when the focus is often on disability and loss

Models of intervention and service provision

- National Service Framework highlights that clients with RPC need services that can respond quickly, provide fast-track equipment and regular reviews
- The standard approach of assessment, intervention, review and exit needs to be adapted
- Assessments and intervention should take place at the clients home where and when possible.



EAT and the National Service Framework

- **Quality Requirement 1: A person- centred service**

People with long term neurological conditions are offered integrated assessment and planning of health and social care needs...

Special needs of people with rapidly progressing conditions:

...may benefit from specialist services including... communication aids and electronic assistive technology. Good care planning will ensure a rapid and flexible response to changing needs so that these services can be provided promptly.

- **Quality Requirement 7: Providing equipment and accommodation**

People with long term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently: help them with their care, maintain their health and improve quality of life

Special needs of people with rapidly progressing conditions:

Rapidly progressing conditions can present a particular challenge for services that provide assistive technology/equipment. Services need to anticipate, identify and regularly review the needs of people with rapidly changing conditions. Providing fast-track equipment can make sure that specialist equipment is prescribed and delivered promptly: maintained in full working order and exchanged flexibly as a person's needs change.

The changing NHS

- Rapidly changing health care system where cost effectiveness is key
 - GP commissioning:
 - A GP is likely to see 1 MND client every 25 years (MND Association)
 - The elephant in the room!
 - (It's not cost effective: does not reduce hospital stay, does not offer 'traditional' health benefits)
- Appropriate outcome measurement and client feedback is vital to demonstrate efficacy
- Develop links with appropriate services to form care pathways
- Reference the National Service Framework to correlate your service to the stated quality requirements

Key learning points



- It is important to have, where possible, an understanding of the likely progression of the condition. This will enable future planning
- Do not assume that the client will want to discuss the future. Always check what they understand and what they would like to know
- Allow time for adjustment. 'Drip feed' ideas and allow time for due consideration. Be prepared that they may not want the most appropriate device – demonstrate and trial to illustrate your reasoning. Choose options that are adaptable and can, where possible, meet changing needs

Key Learning cont...

- Be prepared for change and the need to reassess frequently (and quickly!) – needs a responsive and flexible service
- Work closely with appropriate services to form a ‘team’. Use a **holistic** approach to ensure **all** needs are met in a timely manner
- You maybe the expert in the room – your role may bring you into contact with RPCs more frequently than other health professionals
- Be prepared to sometimes ‘just be’

References

- Motor Neurone Disease, a problem solving approach for GP's and Primary Health Care Team (MND Association, 2007 and 2010 editions)
- The National Service Framework for Long Term Conditions (Department of Health, 2005)
- Cook and Hussey's Assistive Technologies, Principles and Practice (A.Cook and J.Polgar, 2008)
- Communicative Competence for Individuals who use AAC, from research to effective practice (Light, Beukelman, Reichie, 2003)
- Scherer, M.J., Sax, C., Vanbeirvliet, A. , Cushman, L.A. & Scherer, J.V.(2005).Predictors of assistive technology use:The importance of personal and psychosocial factors. *Disability & Rehabilitation*, 27(21), 1321-1331.



Thank you for listening!

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