Overview of the medical guidelines

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Ataxia training day
Exeter, 07 July 2017

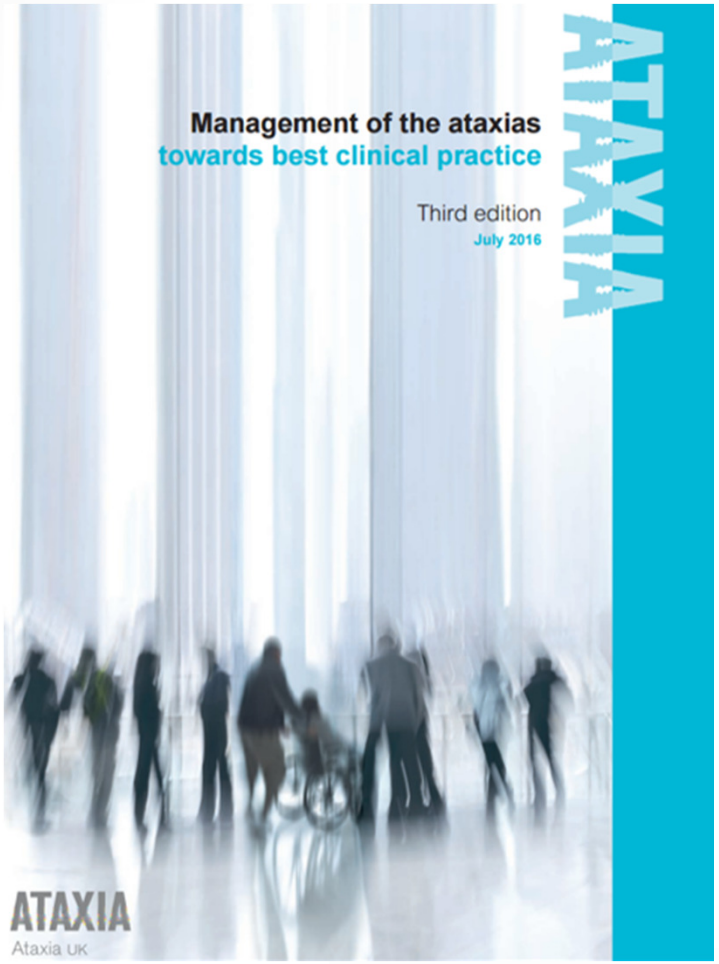
How to update the medical guidelines

- New sections suggested by medical **professionals** and others by **patients**
- Larger document each time so long process
- **Guideline development group**
- Liaising with around 30 **experts** to update and write sections for the new edition
- Making a final large document aimed for HCP
- Production of a summary for **GP**

ATAXIA

Ataxia Medical Guidelines

- Aimed at healthcare professionals to increase awareness
- Third Edition
- Conditions covered:
  - Hereditary ataxias
  - Idiopathic progressive ataxias
  - Specific neurological disorders (progressive ataxia as dominant symptom)



Guideline development

- Guideline Development Group
- 32 Specialist contributors
- **Evidence-based** (graded level of evidence)
  - A (systematic review of PCTs)
  - B (1 or 2 PCTs)
  - C (Cohort studies, single arm studies etc)
  - D (Descriptive studies, clinical experience, not target population
  - GPP (best practice based on expert opinion or clinical experience)

Table 2: Evidence grading scheme for these guidelines

Level of evidence (categorisation of reference materials)[11]

I	Evidence obtained from a systematic review of all relevant randomised controlled trials.
II	Evidence obtained from at least one randomised controlled trial.
III-a	Evidence obtained from one or more controlled trials, pseudo-randomised by alternate allocation, birth date or other planned method.
III-b	Evidence obtained from prospective or retrospective cohort studies with concurrent controls, case-control studies, or interrupted time-series with a control group.
III-c	Evidence obtained from cohort studies with historical controls, two or more single-arm studies, or interrupted time-series without a parallel control group.
IV	Evidence comprises opinions based on clinical experience, descriptive studies or reports by clinical bodies or committees.

Grading of recommendations in the guidelines based on the level of evidence[12]

A.	Body of evidence can be trusted to guide practice; includes one or more level I studies, or several at level II directly applicable to the target population, and demonstrating overall consistency of results.
B.	Body of evidence can be trusted to guide practice in most situations; includes one or two studies rated as level II or several level III studies, directly applicable to the target population, and demonstrating overall consistency of results.
C.	Body of evidence provides some support for recommendation(s) but care should be taken in its application; includes studies rated as III-c, or level I or II with a moderate risk of bias, some inconsistency and applicable to target population with caveats. Population studied is not the target population, however, it would make sense clinically to apply this evidence to target population.
D.	Body of evidence is weak and recommendation must be applied with caution; includes level IV, or level I to IV studies with high risk of bias, inconsistent evidence and that are not applicable to target population.
GPP.	Good practice point: Recommended best practice based on clinical experience and expert opinion.

(Adapted from Reference)

Recommendations

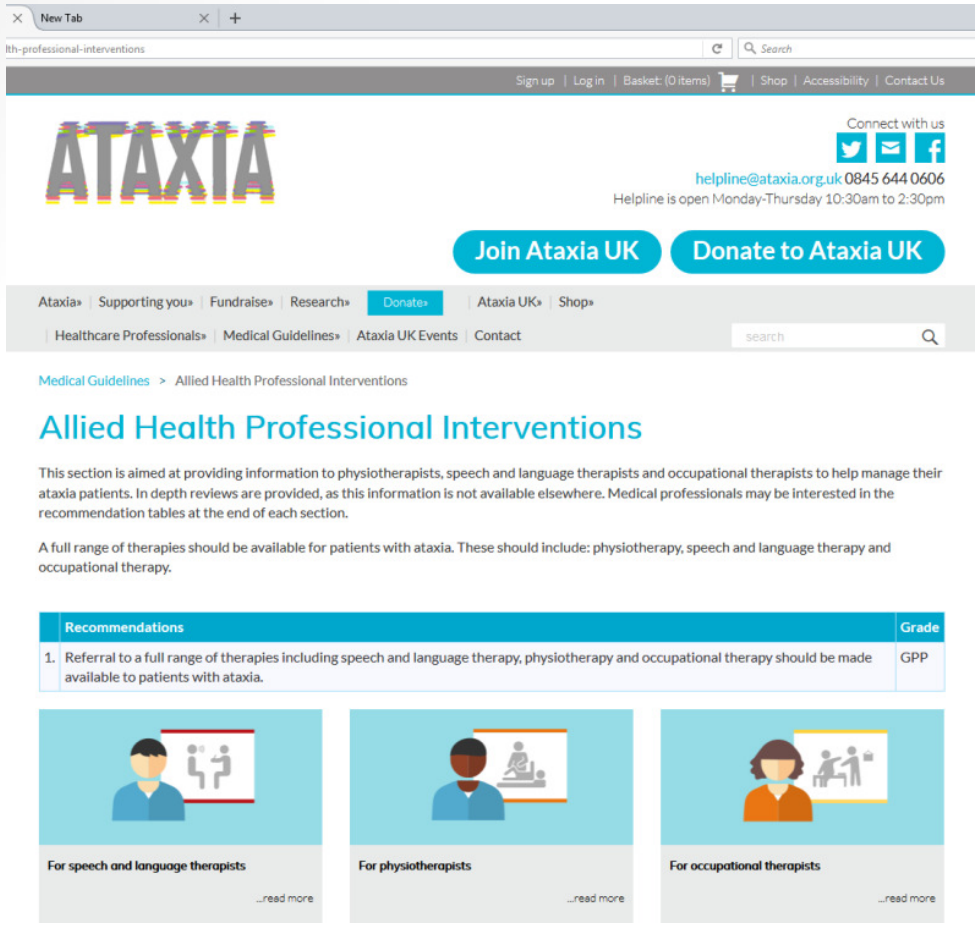
- Diagnosis
- Referrals and follow-up
- Medical interventions eg: spasticity, bladder incontinence, hearing, treatable causes
- Allied health professionals interventions
- Palliative care
- Research

Example of Recommendations for Scoliosis

	Recommendations	Grade
1.	Regular surveillance of the development of scoliosis in Friedreich's ataxia patients (especially children) is recommended as it is important for it to be treated.	GPP
2.	If scoliosis is detected, referral to a physiotherapist and spinal surgeon is recommended.	GPP
3.	For mild scoliosis the patient should be kept under close observation and the spinal surgeon should consider treatment with bracing.	B
4.	For severe scoliosis consider surgery to straighten the spine.	B
5.	Regular follow-up by a spinal surgeon is recommended after an operation on the spine.	B

Dissemination

- Website
- Patients taking to their doctors
- Primary care summary in ‘Guidelines’
- Events
- Professional bodies (COT, ABN, Society of Physiotherapy, etc.)



Work done in collaboration

- **Specialists** are in the best position to update sections on a particular symptom
- Probono work by **Costello**:
- make the document user friendly online
- facilitate update and dissemination with a live PDF
- sections designed on our website
- Collaboration with a online publisher ***Guidelines:*** production of a summary for GP available online

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Guidelines
Summarising clinical guidelines for primary care

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Thank you for listening!
Questions welcome

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