Clinical guidelines

The final frontier of research results

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What is a clinical practice guidelines?

Statements that include recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options

Institute of Medicine (IOM)

Guiding decisions and criteria regarding diagnosis, management, and treatment
Recommendations

Individual with myotonic dystrophy type 1 should have an annual ECG exam performed

How this was agreed on?
Systematic review of the evidences
Assessment of benefits and harms of alternative care options
How this is apply in real life

ONE SIZE FITS ALL: GREAT FOR SOCKS, BAD FOR BELIEFS.

quote from Act Accordingly by Colin Wright
How this is apply in real life

Healthcare professional

Research

You and your family

Individual Clinical Expertise

Best External Evidence

Patient Values & Expectations

EBM
Patients experiences, values and expectations

• The modafinil/ritalin experiences
  • Research demonstrate limited evidences (Cochrane review)
  • Subset of patients
    • Important reported effects

If withdrawn I would not be able to maintain employment and participate in leisure and social activities. To say I would be devastated if it was withdrawn is a massive understatement (Hilton-Jones 2012)
Clinical guidelines vs Website information/review article

- **Clinical guidelines**
  - Systematic review of the literature
  - Quality of the studies systematically reviewed
  - Directive statements
  - Reviewed by a large team of experts
  - Methods you need to follow
  - Limited in its scope

- **Website/review article**
  - Review of the literature
  - Often written by a few researchers or clinicians
  - Often will provide clinical hints
  - Usually no directive statements given.
  - For website, need to make sure it is a reliable source and when it has been updated
  - Permit to present clinical practice update faster
The long path to producing clinical guidelines

• My fingers don’t work like they used to

• A program has been designed to improve strength and showed results
The long path to producing clinical guidelines

The Myotonic Dystrophy Health Index (MDHI)

- The neurologist is using the index and identify that you have problems with your hands and that is strongly affecting your life
WHAT SHOULD I DO?

CLINICAL GUIDELINES WILL HELP YOUR NEUROLOGIST INFORM YOU OF THE POTENTIAL OPTIONS THAT YOU HAVE.
CLINICAL GUIDELINES

• Nursing Integrated Care Pathway
  • Soon available on MDF website
• Occupational Therapy Guidelines
  • Soon available on MDF website
• Medical Guidelines
  • Part is in the toolkit
• Neurology Guidelines
  • Coming soon
IMPLEMENTATION
THE FINAL FRONTIER !!!

Clinical guidelines
BECOME AN INFECTIOUS AGENT

What is a disease vector?

A disease vector is any agent that carries and transmits an infectious pathogen into another living organism.