



# 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**



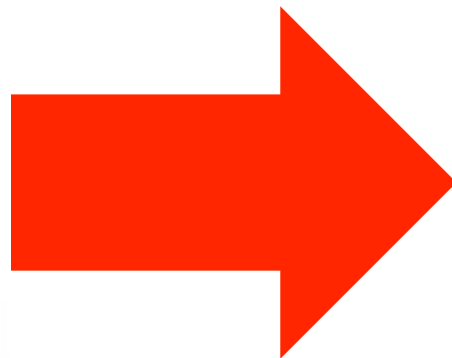
## RECOMMENDATIONS

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

**How this was agreed on ?**

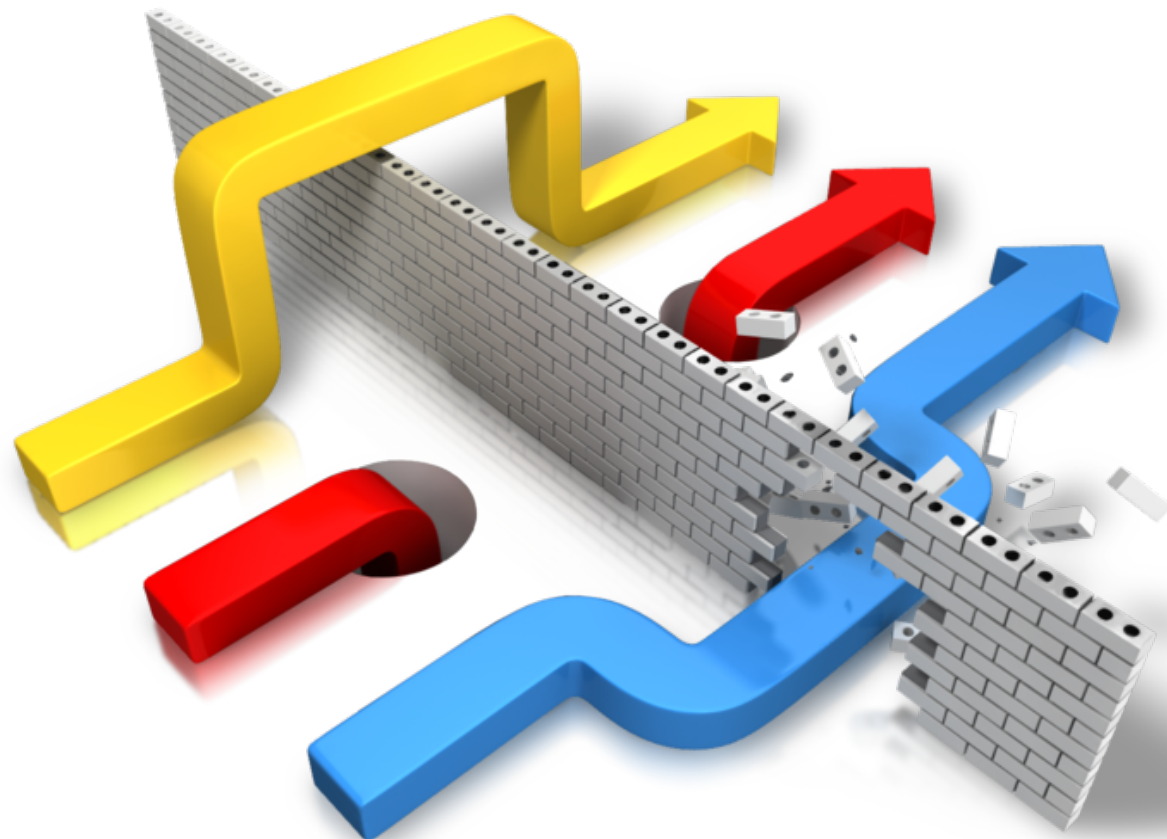


## SYSTEMATIC REVIEW OF THE EVIDENCES





## ***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**



## **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If withdrawn I would not be able to maintain employment and participate in leisure and social activities. To say I would be devastated if it was withdrawn is a massive understatement (Hilton-Jones 2012)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 ?

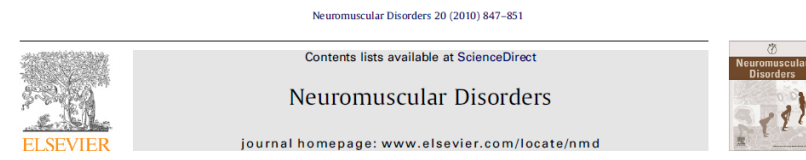
**CLINICAL GUIDELINES WILL HELP YOUR  
NEUROLOGIST INFORM YOU OF THE  
POTENTIAL OPTIONS THAT YOU HAVE**





## 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



Health supervision and anticipatory guidance in adult myotonic dystrophy type 1

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## IMPLEMENTATION THE FINAL FRONTIER !!!



**Clinical guidelines**





## BECOME AN INFECTIOUS AGENT

