Myositis UK: COVID-19 Webinar

15-3-20

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GREATER MANCHESTER Neurosciences CENTRE

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The University of Manchester

CfMR Centre for Musculoskeletal Research

Salford Royal NHS
NHS Foundation Trust

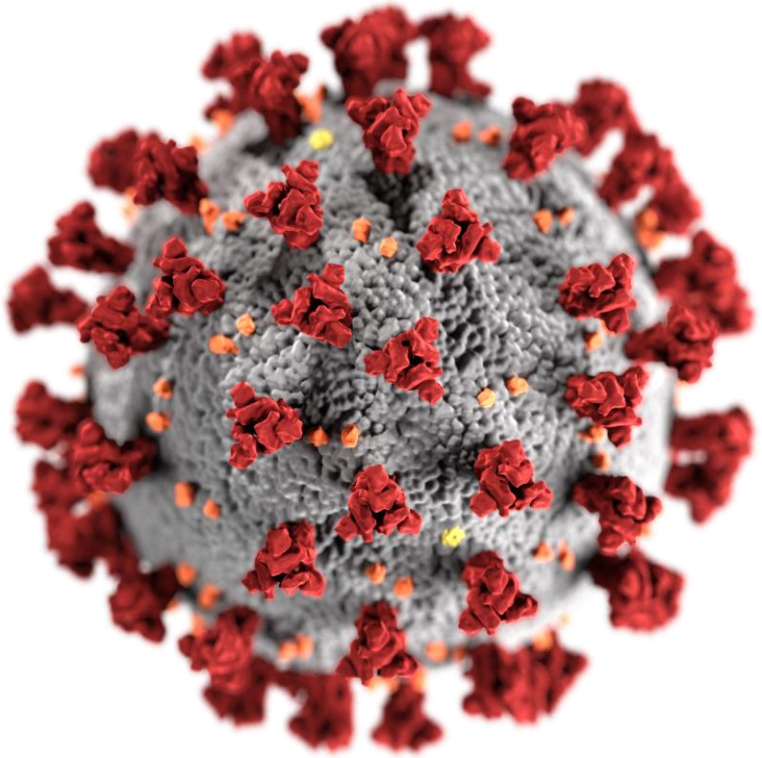
NHS
National Institute for Health Research

Disclaimers

- We **aren't experts** in infectious diseases or the management of coronavirus specifically.
- We **aren't paediatricians**
- There are still many **unknowns**
- The situation is **changing** minute by minute
- Information given here will be **general and reflects personal views**
- We **cannot** give you specific/individualised advice about managing your condition
- Please **contact your GP or specialist** if you have any concerns

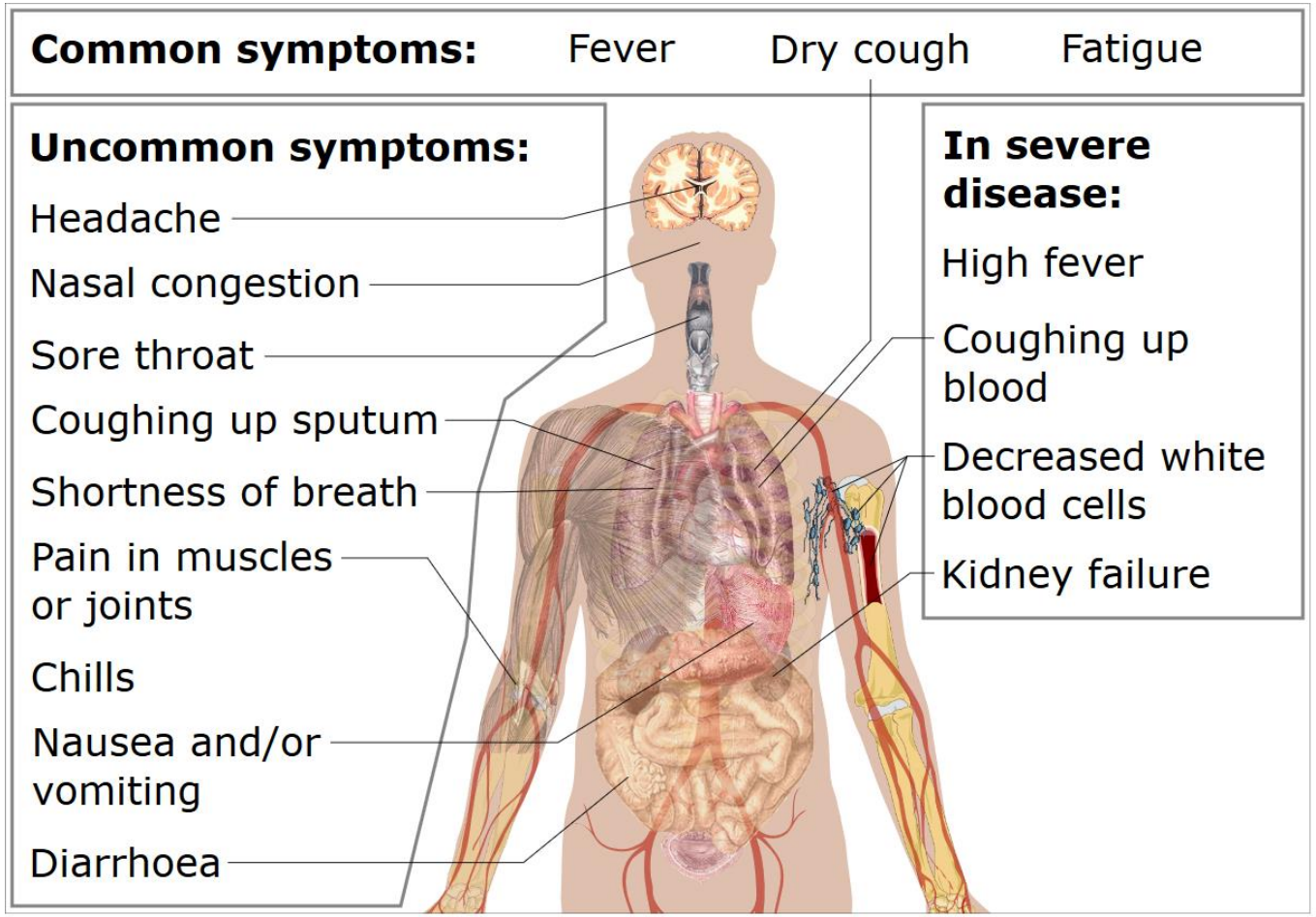
Novel Coronavirus / COVID-19 / SARS-CoV-2

- Wuhan, China
- First case ~ Nov 2019
- Likely transmitted to humans from **bats**
- Human-to-human transmission via **respiratory droplets**
- Initially spread to South Korea, Iran and Italy
- **Pandemic** declared 11th March 2020



Key symptoms

1. Persistent cough
2. Shortness of breath
3. Fever



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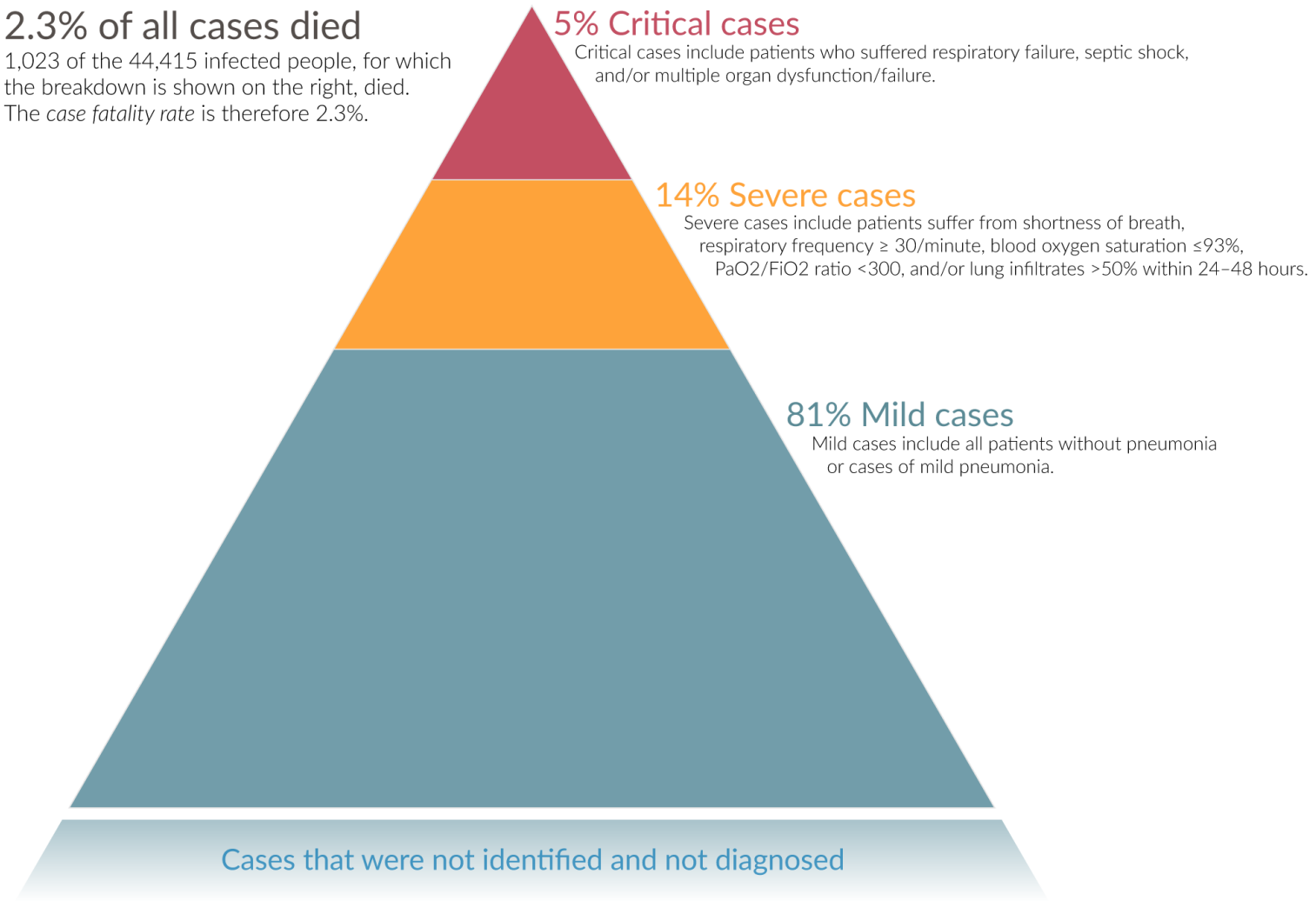
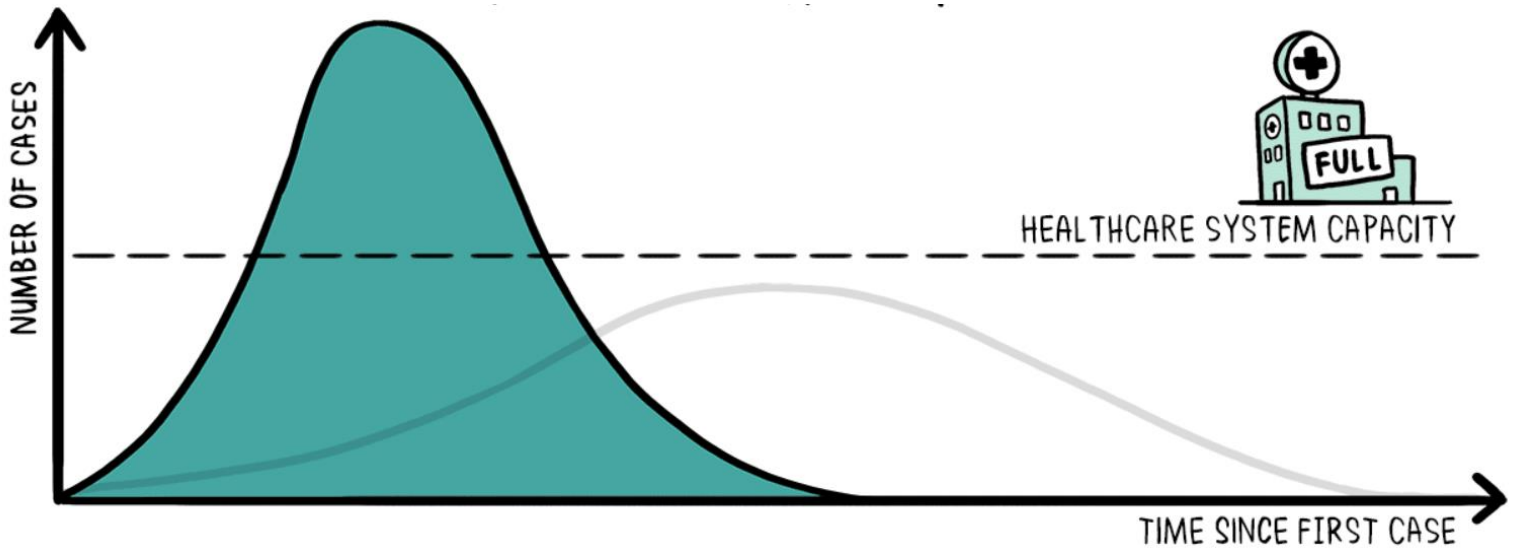
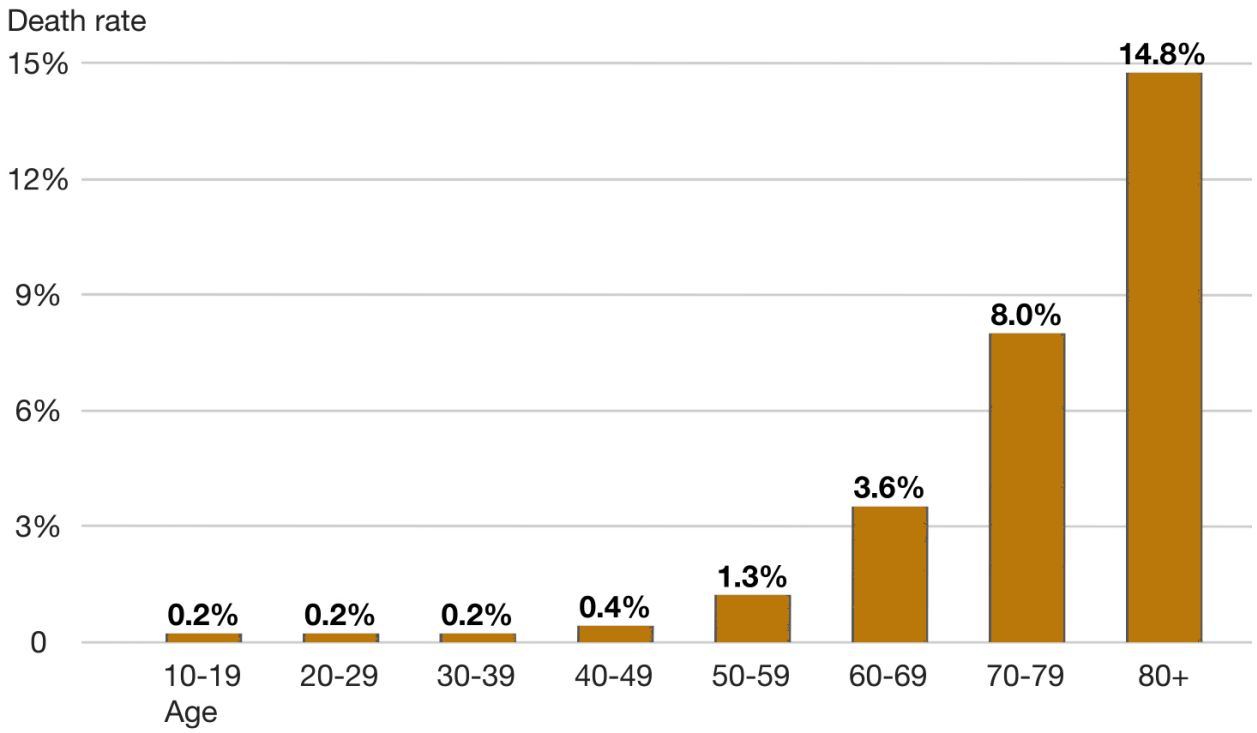


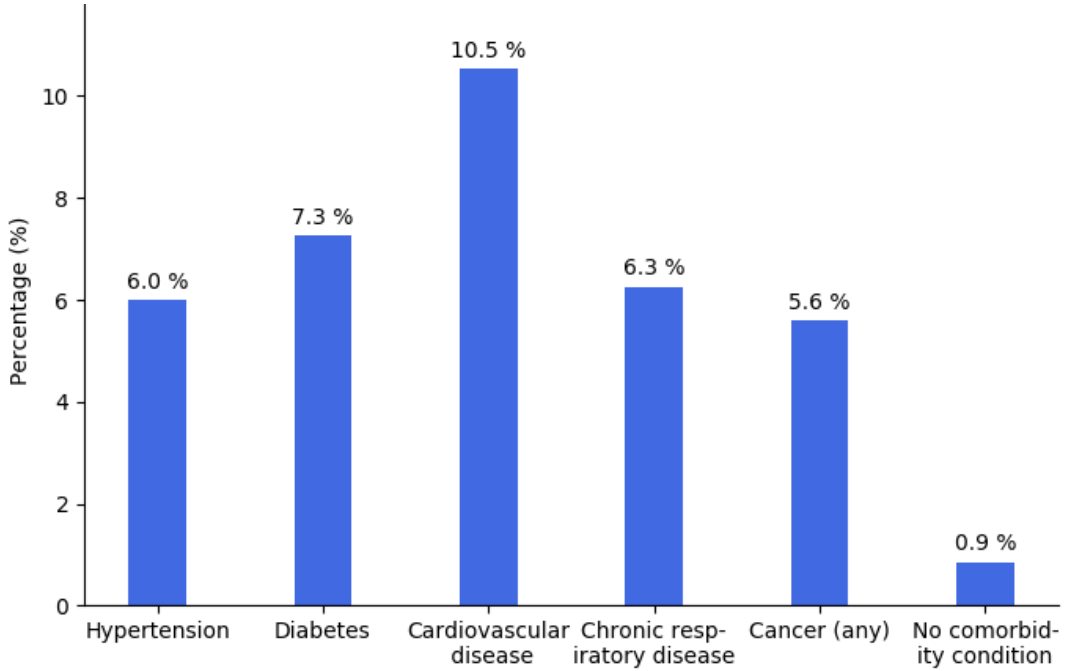
Key problems

- **New virus** - No immunity - No vaccine
- **Rapid spread** - Highly contagious - Asymptomatic infectious period
- **Some** patients become very sick
- Health care systems become quickly **overloaded**



High risk groups – age and other illnesses





What to do - general

- Check **gov.uk** or **nhs.uk** website regularly for up to date info

What to do - general

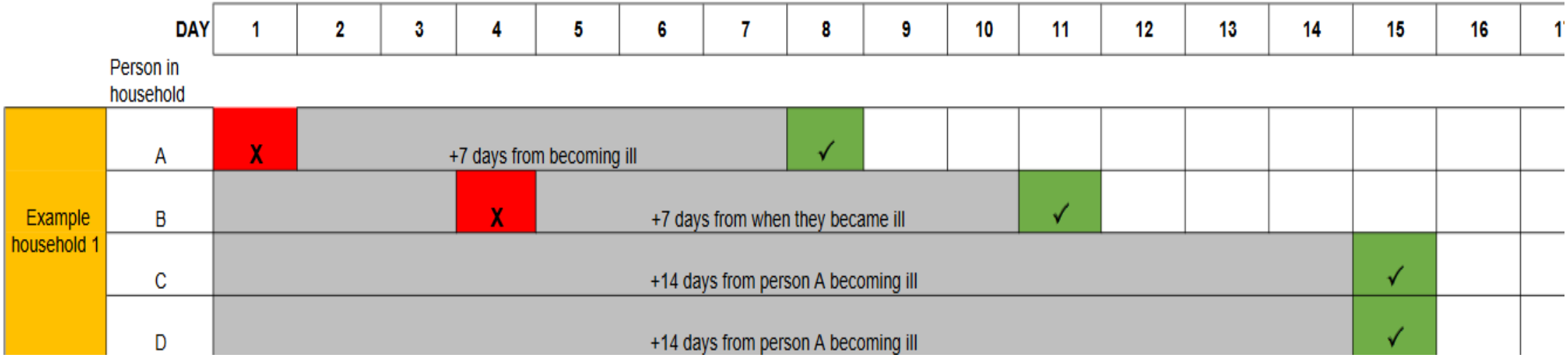
- **Strict** social distancing
  - 2m separation
  - “Only go outside for food, health reasons or work”

What to do - general

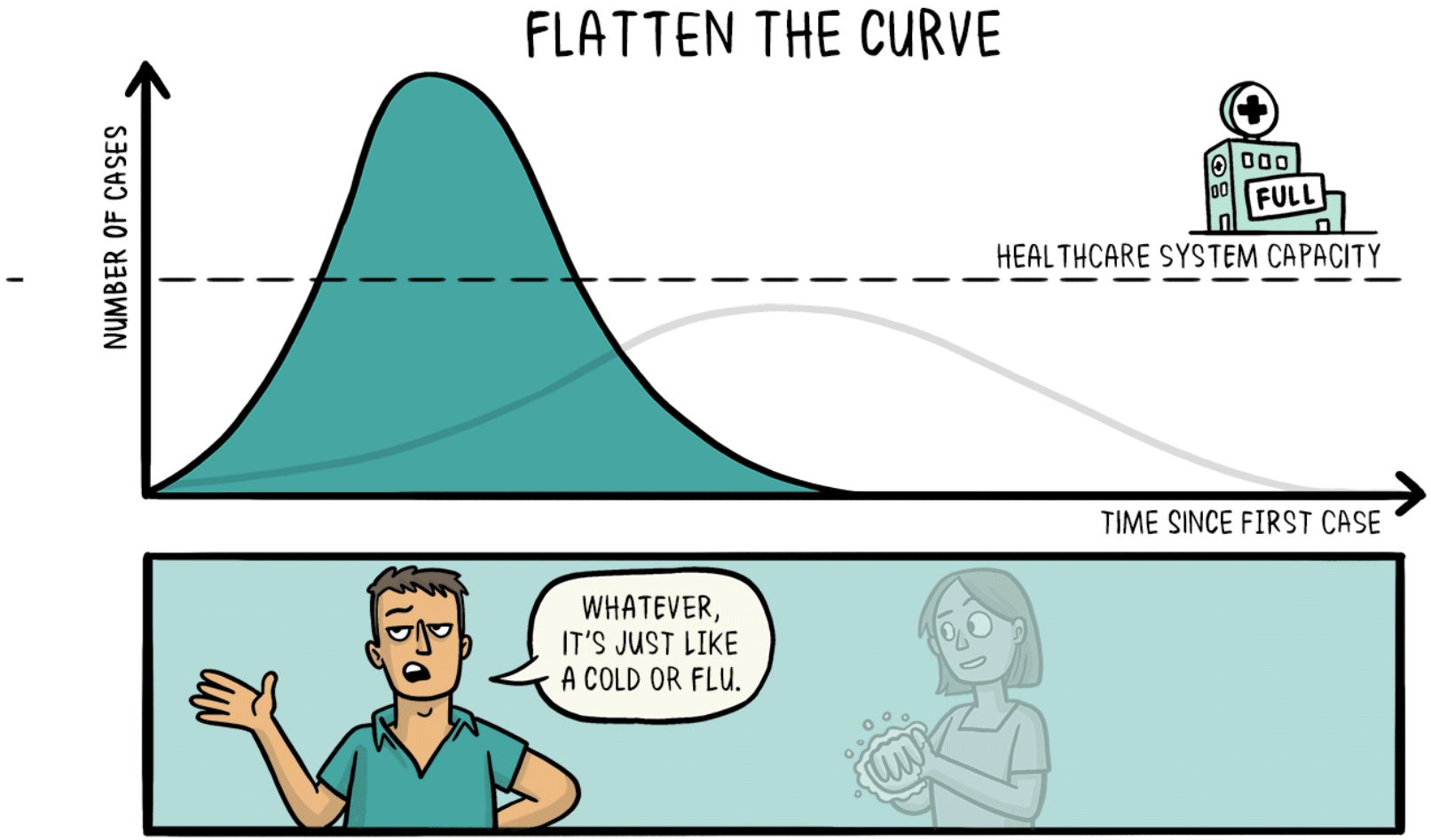
- **Strict** social distancing
- **Meticulous** hand washing
  - Soap is fine
  - Especially when returning home
  - Avoid touching face
  - Sneeze in to a tissue, not your hands

What to do - general

- **Strict** social distancing
- **Meticulous** hand washing
- **Self-isolation** if you **have symptoms**
  - Household to stop work and stay at home



What to do - general



What to do – high risk

- Criteria have been defined for **highly vulnerable** people:
  - Solid **organ transplant** recipients.
  - People with specific **cancers**.
  - People with **severe respiratory conditions** including all cystic fibrosis, severe asthma and severe COPD.
  - People with **rare diseases and inborn errors of metabolism that significantly increase the risk of infections** (such as SCID, homozygous sickle cell).
  - People **on immunosuppression therapies** sufficient to significantly increase risk of infection.
  - Women **who are pregnant with significant heart disease**
- **See here for risk stratification table from the BSR**

What to do – high risk

- These individuals are advised to practice **“Shielding”** for at least the next 12 weeks:
  - Strictly **avoid contact** with those displaying symptoms of coronavirus.
  - Do **not** leave your house.
  - Do **not** attend any gatherings.
  - Do **not go out** for shopping, leisure or travel and, when arranging food or medication deliveries, these should be left at the door to minimise contact.

What to do – high risk

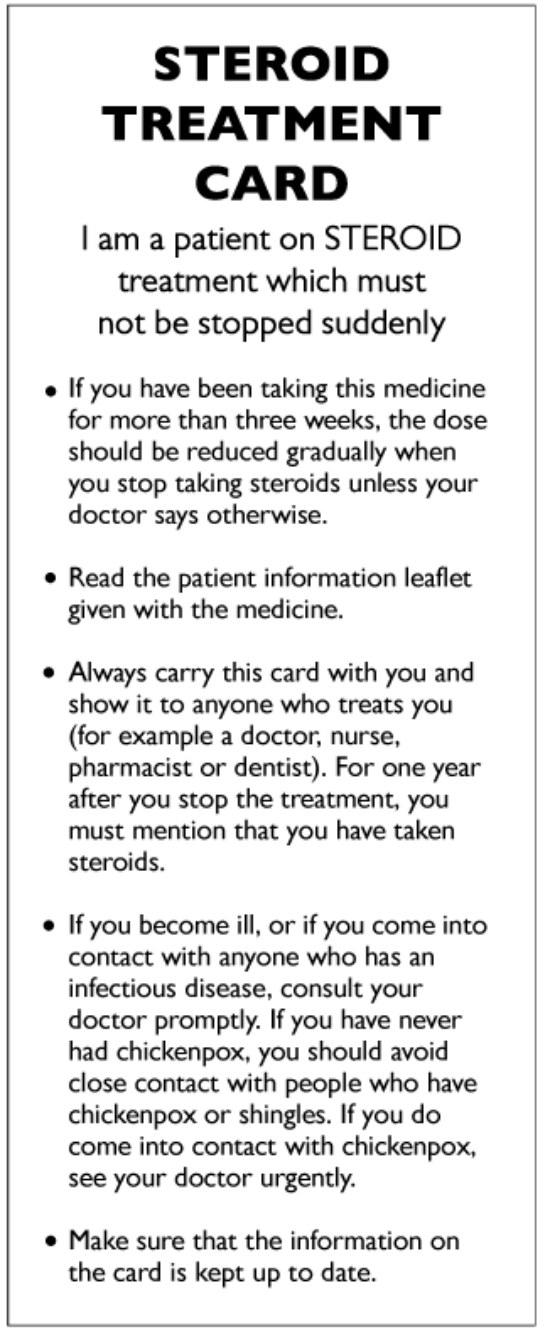
- Additional help is available (food, medicines, additional care) for these individuals if required:
  - A letter from the NHS is being sent to those already identified as high risk
  - They can also self register here: gov.uk/coronavirus-extremely-vulnerable

Am I in this high risk group?

- Patients with myositis can be particularly vulnerable to respiratory infections:
  - On immunosuppression
    - Especially prednisolone >20mg, DMARDS, biologics, JAK inhibitors
    - Combination therapy
  - Respiratory muscle weakness
  - Interstitial lung disease
  - Problems swallowing
- Have a low threshold for **shielding**

What to do: *Decisions must be individualised*

- Some general rules:
- DO NOT SUDDENLY STOP TREATMENT, especially steroids
- Make sure you have a good supply of your medications
- Speak to specialist / GP
  - Your specialist may try to maintain you on the lowest steroid dose possible
  - If you become unwell you may need a higher dose of steroids
  - Scheduled biologics (e.g. rituximab) could potentially be postponed
  - Blood monitoring frequency may need to decrease – **avoid hospital**



STEROID TREATMENT CARD

I am a patient on STEROID treatment which must not be stopped suddenly

- If you have been taking this medicine for more than three weeks, the dose should be reduced gradually when you stop taking steroids unless your doctor says otherwise.
- Read the patient information leaflet given with the medicine.
- Always carry this card with you and show it to anyone who treats you (for example a doctor, nurse, pharmacist or dentist). For one year after you stop the treatment, you must mention that you have taken steroids.
- If you become ill, or if you come into contact with anyone who has an infectious disease, consult your doctor promptly. If you have never had chickenpox, you should avoid close contact with people who have chickenpox or shingles. If you do come into contact with chickenpox, see your doctor urgently.
- Make sure that the information on the card is kept up to date.

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PHYSIO in IIM

Myositis UK
Online Meeting
Wednesday 25th March 2020

Will Gregory
Consultant Physio
Salford Royal Hospital

AIMS and OBJECTIVES

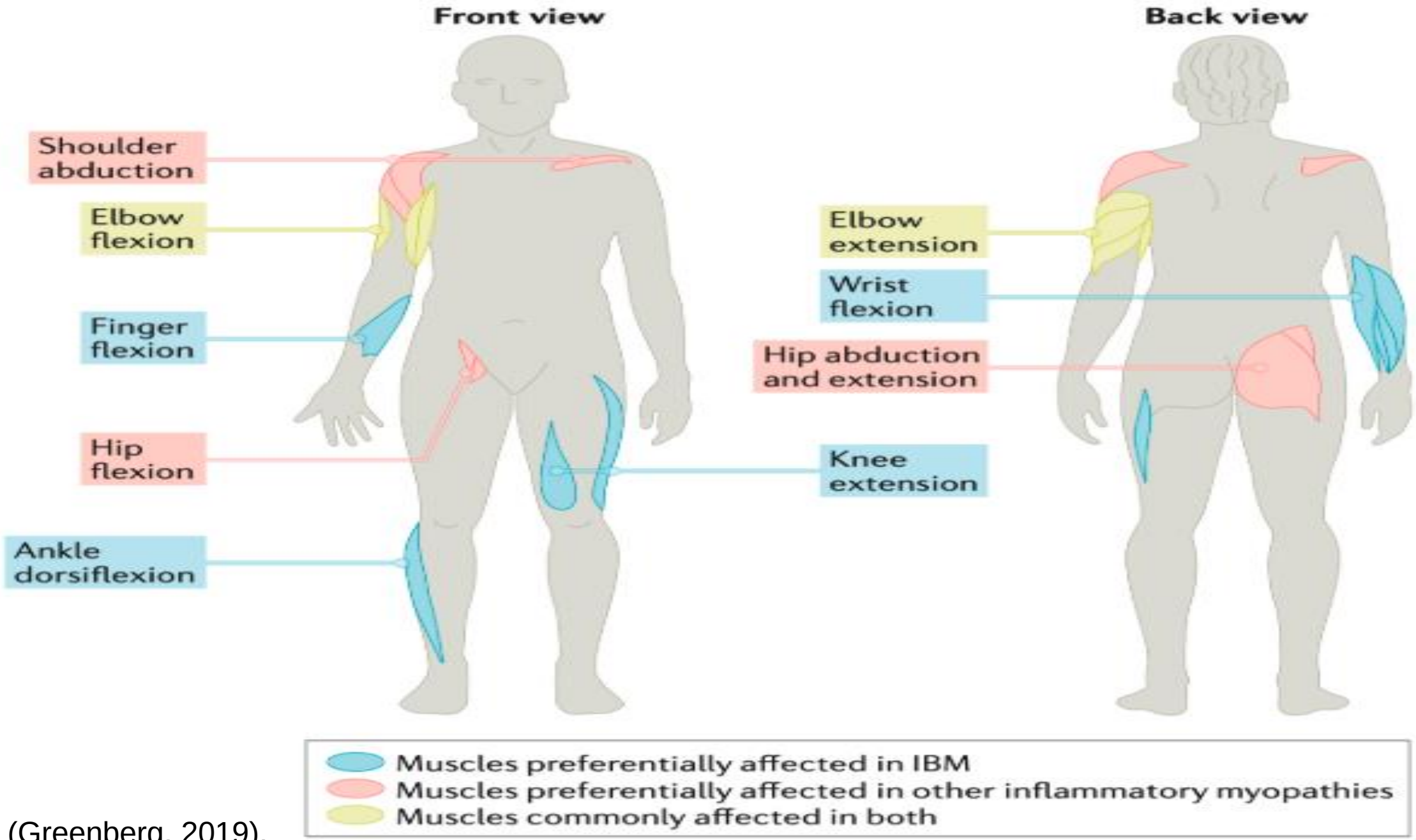
To consider evidence based physiotherapy / rehabilitation and consider its application in your home

- History of treatment
- Evolving evidence base
- Best practice guidance

INTRODUCTION

The inflammatory myopathies represent the largest group of acquired and potentially treatable causes of skeletal muscle weakness

- They are classified into three major groups:
  - polymyositis (PM),
  - dermatomyositis (DM)
  - inclusion body myositis (IBM)



(Greenberg, 2019).

More than just muscle inflammation

Muscle inflammation

- Vascular changes in muscle

(Cea 2002; Okoma et al. 2007; Grundtman et al. 2008)

- Reduced ATP and creatine phosphate levels

(Park & Olsen 2001)

- ↓ type I fibres and ↑ type IIc fibres

(Dastmalchi et al. 2007)

Broader effects of living with IIM

- Steroid-induced myopathy

(Gupta 2013)

- Muscle cachexia from chronic systemic inflammation
- Disuse atrophy and Deconditioning

(Nader & Lundberg 2009)

SLIDE COURTESY OF JADE SKEATES.

Cea et al. (2002) Brain 125 (7): 1635-1645; Okoma et al. (2007) International Journal of Clinical Practice 61(4): 684-689;; Grundtman et al. (2008) Arthritis and Rheumatism 58(10):3224-38; Park & Olsen (2001) Current Rheumatol Rep 3: 334—345;

Health Assessment Questionnaire

Please check the one response that best describes your usual abilities **IN THE PAST SEVEN DAYS:**

	Without **ANY** difficulty	With **SOME** difficulty	With **MUCH** difficulty	**UNABLE** to do
DRESSING & GROOMING Are you able to: -Dress yourself, including tying shoelaces and doing buttons	_____	_____	_____	_____
-Shampoo your hair?	_____	_____	_____	_____
ARISING Are you able to : -Stand up from an armless straight chair?	_____	_____	_____	_____
-Get in and out of bed?	_____	_____	_____	_____
EATING Are you able to: -Cut your meat?	_____	_____	_____	_____
-Lift a full glass to your mouth?	_____	_____	_____	_____

Modern Evidence Base for Exercise

Recent Onset PM and DM

Alexanderson H et al. Scand J Rheum 2000;29:295-301

Alexanderson H et al. J Rheumatol 2014;41:1124-32

- Well tolerated and safe - does not increase CK or inflammation in muscle tissue
- Can improve muscle function, aerobic capacity and quality of life

Low-active PM/DM

Alexanderson H et al. Rheumatology 1999;38:608-11

Dastmalchi M et al. Arthritis Rheum 2007;57:1303-10

- Well-tolerated, does not increase CK or inflammation in muscle tissue
- Can improve muscle function and quality of life
- Normalize proportion of type-1, oxidative muscle fibers – explaining the improved muscle endurance

Exercise improves muscle function, aerobic conditioning and quality of life in IIM patients

- Safe & therapeutic benefits of exercise (active and/or recent onset disease)
- Several exercise programs based on resistance training, aerobic exercise or combination, up to 12 weeks duration
- **No evidence that exercise has deleterious effects on disease activity**
- Supervised resistance training in combination with aerobic exercise **starting 4 weeks after initiation of pharmacotherapy, or as soon as patients are able to perform exercise**

Alexanderson H.
Physical exercise as a treatment for adult and juvenile myositis.
J Intern Med 2016;280:75-96.

Is exercise safe if you have Myositis?

Habers & Lundberg – Systematic review, 2011

- No worsening of disease activity
- No change in pain reporting
- Anti-inflammatory effect on systemic cytokines? (Nader & Lundberg 2009)

SLIDE COURTESY OF JADE SKEATES

Current Opinions in Rheumatology 21:699-603.

Other non-pharmacotherapeutic measures

- **Pulmonology collaboration** in patients with associated lung disease
- **Speech therapy** & aspiration precautions for patients with pharyngeal and oesophageal involvement
- **Osteoporosis prevention and treatment**
- Appropriate **immunizations** prior to initiation of immunosuppressive therapy and **pneumocystic prophylaxis** in patients receiving high dose glucocorticoids & other immunosuppressants
- **Counselling, psychological and social work** support.

Mann & Vencovsky. Treatment of Idiopathic Inflammatory Myopathies (Chapter) in Chinoy H. & Cooper R.G. (ed). Myositis - Oxford Rheumatology Library. (Oxford University Press) 2017

Physiotherapy Management

Home exercise program PM/DM

1. Warm-up

2. Shoulder mobility

3. Grip strength

4. Strength knee extensors

5. Strength shoulders

6. Strength hip extensors

8. Strength hip flexors

7. Strength neck flexors and trunk

- Improved muscle function and health (Physical, Pain, Fatigue) without increased muscle Inflammation
- Signs of reduced inflammation in Patients with low disease activity

Correct application of the research-based exercise programme

- Start exercise about 4 weeks after diagnosis
- Measure muscle function before starting
- Short exercise sessions (15 minutes), but for frequent (4-5 days per week)
- Vary upper-and lower limb tasks so that you don’t overexert any muscle groups
- First weeks of exercise: Perform repetitions so that your rating of exertion after completion of program does not exceed 3 on Borg CR-10 scale
- After about 4 weeks, increase repetitions or loads to correspond to exertion of 5-7 on the Borg scale
- If it is too strenuous to the whole program at once, divide it into two sessions and rest in-between
- You can combine this program with a walk to improve your aerobic capacity
- This program can be used even if you have the need for extra oxygen supply

Weak = Light

The Salford Physio IIM Assessment

- Version 2: adapted from clinician and patient feedback
- To fit into a 15-20 minute consult
- Includes PROM and muscle strength tests
- Normative data is aspirational or for re-assurance of those near to full m/s
- Aim to form a conversation starting point:
  - Re-enforcing current HEP
  - Guiding adaptation to HEP
  - Encouraging more (or some) HEP
- Currently undertaken as a part of MDT appointment - usually prior to consultant review

MANUAL MUSCLE TESTING MMT8: Date: / / 19

Muscle Groups	Grade
Axial	
(7)Neck Flexors	
Proximal	L R
(1) Shoulder Adductors	
(2)Elbow Flexors	
(8)Hip Extensors	
(6)Hip Abductors	
(4)Knee Extensors	
Distal	
(3)Wrist Extensors	
(5)Ankle Dorsiflexors	
TOTAL SCORE	

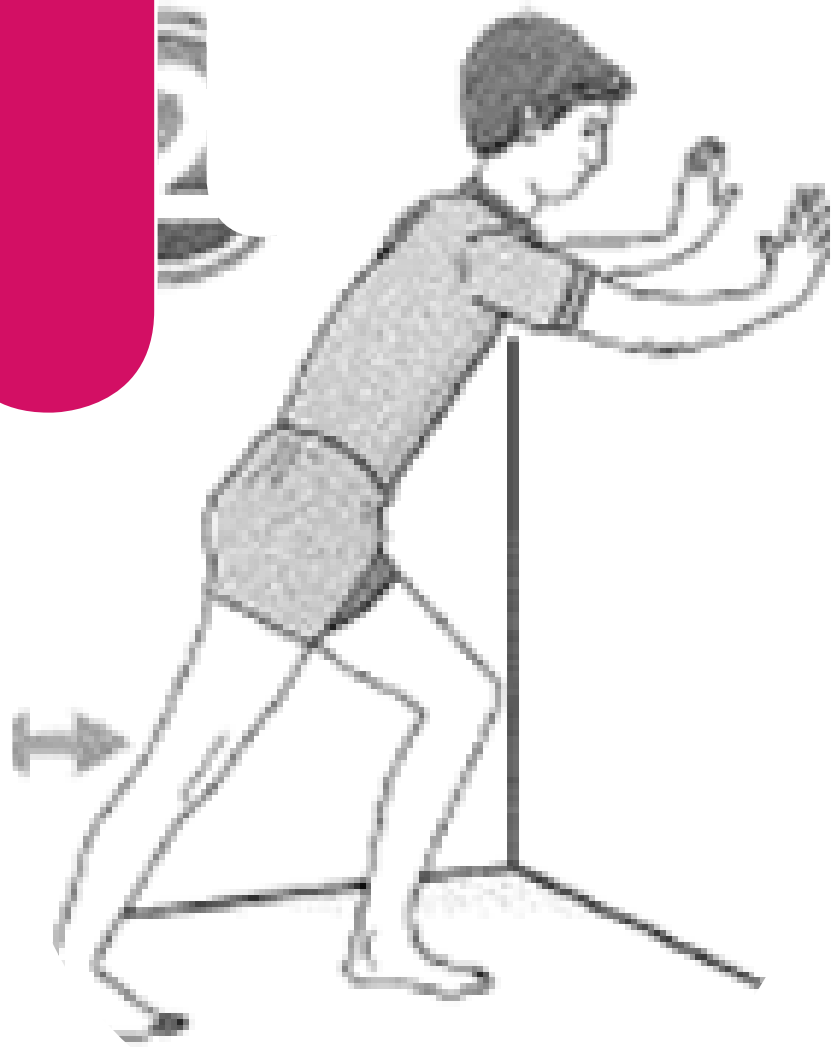
MMT GRADING:

	FUNCTION OF THE MUSCLE	GRADE
No Movement	No contraction felt in muscle	0 / 0
	Feeble contraction felt in muscle, but no movement of part	T / 1
	MOVEMENT IN HORIZONTAL PLANE	
Test Movement	Moves through partial range of motion	1 / 2-
	Moves through complete range of motion	2 / 2
	ANTIGRAVITY POSITION	
	Moves through partial range of motion	3 / 2+
Test Position	Gradual release from test position	4 / 3-
	Holds test position (no added pressure)	5 / 3
	Holds test position against slight pressure	6 / 3+
	Holds test position against slight to moderate pressure	7 / 4-
	Holds test position against moderate pressure	8 / 4
	Holds test position against moderate to strong pressure	9 / 4+
	Holds test position against strong pressure	10 / 5

Task	Left (Borg CR- 0 - 10)	Right (Borg CR-0 -10)	Score
Shoulder Flexion			
Head Lift			
Hip Flexion			
THE FUNCTIONAL INDEX 3	Total Left=	Total Right=	

TOTAL HAQ SCORE:		Dressing Arising Eating Walking Hygiene Reach Grip Activities
EQ-5D:		Mobility, Self Care, Usual Activities, Pain /Discomfort, Anxiety / Depression

Dominant hand:	Left	Right
Hand grip Strength:	kg	Kg
Shoulder Abd Strength:	kg	Kg
Quadriceps Strength:	kg	Kg
Other Outcomes:	Weight kg	Physio Advice (if given):
Patient rated global /10	Height cm	
Other:	BP / HR	



Salford H.E.P.

In DRAFT format at present. Please contact Myositis UK to get a copy for patient and public review process

- Part 2 for people with IBM
- Part 1 for all other IIM diagnoses

- Part 1 from the team at the Karolinska, Sweden

- Part 2 from the Australian team

Myositis UK Online Meeting, Wednesday 25th March 2020

Will Gregory, Salford Royal, Northern Care Alliance.

@PhysioWIllGreg