

A and E/ emergency care for DMD

Better safe than sorry

A and E guidelines

- Developed at the request of Action Duchenne who were very concerned about risk to people with Duchenne presenting to A and E
 - Lack of knowledge
 - Lack of previous clinical data
- Produced by Dr Tracey Willis from the International Care Standards document
- Don't panic- hopefully this is something you will never need to use!

What do the guidelines cover?

- Basic principles- don't be nihilistic
- The key “problem” areas
 - What do with respiratory problems
 - Cardiac presentations
 - Steroids- how to cover missed doses
 - What to watch out for as possible steroid side effects
 - Getting anaesthetics as safely as possible
 - What to do with broken bones?
- Caution: care in the acute situation needs to be delivered based on individualised assessment- these are only guidelines

How to use the guidelines

- Get your copy and keep it safe!
- Make sure you keep up to date with the clinical data at your appointments
- Know who the doctors are who are looking after your son and where you can access them
- If you do go into hospital, let your care team know you are there and who to contact
- Provide feedback on these guidelines if you do need to use them