



## Important information

The following sections are to be filled in by you, or on your behalf by a parent/guardian or carer:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Tel: \_\_\_\_\_ Email: \_\_\_\_\_

Date of birth: \_\_\_\_\_ NHS number: \_\_\_\_\_

### Emergency contact details (next of kin):

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Contact number: \_\_\_\_\_

**Please inform my lead clinician or key worker (care advisor, clinical nurse specialist, physiotherapist, GP etc.) of all hospital admissions, including planned procedures:**

My key worker is: \_\_\_\_\_

Tel: \_\_\_\_\_ Email: \_\_\_\_\_

### Other important documents to be aware of (and where they are held):

e.g. Respiratory care plan held in patient records

1. \_\_\_\_\_

2. \_\_\_\_\_

**This document is a patient-held record. It provides a brief summary of my key care needs and the specialists who should be consulted if I am admitted to hospital. It is a modified version of one developed by Route 66 in collaboration with the UK Transition Taskforce led by Together for Short Lives.**

While every reasonable effort is made to ensure that the information in this document is complete, correct and up-to-date, this cannot be guaranteed and Muscular Dystrophy UK shall not be liable whatsoever for any damages incurred as a result of its use. Muscular Dystrophy UK does not necessarily endorse the services provided by the organisations listed in our factsheets.

## About me

I live with:

Other people important to me:

**Who should people talk to about me and my condition?**

- Me
- Someone in my family: \_\_\_\_\_
- Other: \_\_\_\_\_

**I need someone with me:**

- All the time
- Getting up in the morning
- For bathing and toileting
- For turning at night
- At the following times: \_\_\_\_\_
- I do not need help

**I have difficulties with (e.g. verbal communication, hearing, eyesight):**

- Yes
- No

If yes, explain:

My preferred language is: \_\_\_\_\_

## About my neuromuscular condition

My condition is called: \_\_\_\_\_

My neuromuscular specialist is: \_\_\_\_\_

Contact details (telephone / email): \_\_\_\_\_

What makes me or my symptoms / my condition worse?

What makes my symptoms / condition better?

Other important things to know about my condition (e.g. precautions to be taken with general anaesthetics, some muscle conditions can be associated with abnormal liver tests or be made worse by electrolyte changes):

How I move around, what equipment I need for transfers:

My physiotherapy routine (inc. splints, stretches, positioning):

Personal care (washing, dressing, toileting):

Sleep (inc. positioning, mattress, equipment):

## My medicines and allergies

Allergies or adverse reactions:

1) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

2) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

3) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

4) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

5) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

6) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

7) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

8) Medication: \_\_\_\_\_

Dose \_\_\_\_\_

The following sections are to be filled in by the relevant health professional

## Respiratory care

\* please tick as appropriate

1)  I usually have no problem with my breathing muscles\*

I usually have some weakness in my breathing muscles\*

2) My breathing tests are usually (if known):

FVC L while sitting \_\_\_\_\_ while lying \_\_\_\_\_

P cough flow L/min \_\_\_\_\_

Oxygen saturations % \_\_\_\_\_

3)  I can usually cough on my own\*

My carer helps with my chest physio\*

I need help from a specialist chest physio\*

I use a cough assist device\*

4) I normally require NIV:

only at night

during the day

24 hours

never

5) I normally require CPAP:

only at night

during the day

24 hours

never

### WARNING:

**Please do not give me oxygen without my ventilator.**

**Please do not give me oxygen, without monitoring my carbon dioxide levels.**

6) My pressure settings are:

NIV: \_\_\_\_\_ CPAP: \_\_\_\_\_

If I am admitted with breathing problems, please contact the following for advice about managing my condition:

Dr: \_\_\_\_\_ Respiratory Consultant Physician

Tel: \_\_\_\_\_

or my respiratory nurse/physiotherapist:

Name: \_\_\_\_\_

Tel: \_\_\_\_\_

## Cardiac management

My condition may  / may not  be associated with cardiac dysrhythmia or cardiomyopathy

\* please tick as appropriate

\*\* if known

I have no known heart problems\*

I have minor heart rhythm changes on ECG\*

First degree HB / BBB / Left axis deviation\*

I have previously had a very abnormal rhythm / cardiac arrest\*

I have a pacemaker\* – please specify type of pacemaker\*\* \_\_\_\_\_

I have a cardioverter defibrillator (ICD)\*

My last pacemaker / ICD check was on   /   /

My last echocardiogram was on   /   /

At: (name of hospital) \_\_\_\_\_

I have reduced ventricular function\*

The ejection fraction was\*\* \_\_\_\_\_

I have been diagnosed with a cardiomyopathy\*

My heart valves are: normal  / abnormal  \*

Please contact my cardiologist for further advice:

Dr: \_\_\_\_\_

Tel: \_\_\_\_\_

## Anaesthetic management

I am at risk of anaesthetic complications because of my neuromuscular condition. However my condition should NOT be a contra-indication to having an anaesthetic. **Early consultation with a senior consultant anaesthetist for neuromuscular conditions is essential** to ensure the best management for me.

Consideration should be given to alternatives to general anaesthesia. (Could sedation, local, regional or epidural anaesthesia, etc, be used, provided I can be comfortable if the procedure is performed under this type of anaesthesia?)

- 1) I am  / am not  at increased risk of cardiac dysrhythmia and ventricular impairment.
- 2) I may  / may not  be extremely sensitive to, or develop a reaction to, certain anaesthetic agents, including malignant hyperthermia.
- 3) I am  / am not  at risk of delayed recovery after anaesthesia or sedation and will need a higher level of post-operative care.
- 4) I may  / may not  be at high risk of pneumonia because of aspiration and weak respiratory muscles.
- 5)  I may be more sensitive to the effect of opioid analgesics and sedatives as these may worsen my breathing function and consciousness.

**For further anaesthetic advice, please contact:**

Dr: \_\_\_\_\_ at: \_\_\_\_\_

## Acute trauma

**In the event of injury, there are several things to consider.**

- 1) My bones are osteopenic and I may sustain fractures with low impact trauma. Please consider this possibility even after apparently minor falls or impact.
- 2) Please be aware of the risk of fat embolism after falls, even without fractures.
- 3) **Anaesthesia** – please see separate sections about anaesthesia, cardiac and respiratory complications.
- 4) If I or my limbs are immobilised for even short periods of time, my muscle condition makes it much more likely for my muscles to waste away very quickly and for joint contractures to develop. If at all possible, alternative treatment approaches should be considered such as **external fixators** for fracture management. I will need to be mobilised with physiotherapy input at the earliest opportunity. Please discuss any planned management with my neuromuscular specialist.
- 5) I will need intensive physiotherapy and rehabilitation requiring liaison between acute musculoskeletal and neuromuscular physiotherapists.
- 6) I may be **more sensitive** to the effects of opioid analgesics and sedatives.

**Specialist neuromuscular physiotherapy advice may be obtained from:**

Tel: \_\_\_\_\_

## Speech and swallowing

\* please tick as appropriate

- Sometimes my condition affects my speech\*
- I don't have problems swallowing\*
- I do have problems swallowing\*
- I need to have sips of fluid to help me swallow food\*
- I need to have food thickeners so I can swallow safely\*
- I have a PEG tube for most of my nutrition but can have some foods orally\*
- I can only have food through a PEG\*
- I take medication for constipation\*

Be aware that if unwell I may need help opening my bowels. Constipation may cause respiratory and breathing difficulties as a secondary complication.

Please consult my Speech and Language Therapist (SALT): \_\_\_\_\_

Tel: \_\_\_\_\_

and my dietician: \_\_\_\_\_ Tel: \_\_\_\_\_

## My neuromuscular contacts

**My neuromuscular specialist is:**

Dr: \_\_\_\_\_

Email: \_\_\_\_\_

Tel: \_\_\_\_\_

**My cardiologist is:**

Dr: \_\_\_\_\_

Email: \_\_\_\_\_

Tel: \_\_\_\_\_

**My respiratory physician is:**

Dr: \_\_\_\_\_

Email: \_\_\_\_\_

Tel: \_\_\_\_\_

**My care advisor is:**

Name: \_\_\_\_\_

Email: \_\_\_\_\_

Tel: \_\_\_\_\_

**My GP is:**

Dr: \_\_\_\_\_

Email: \_\_\_\_\_

Tel: \_\_\_\_\_



## My daily routine

My morning routine:

My afternoon routine:

My evening routine:

My night-time routine:

## Notes