



### **For people with Friedreich's ataxia (FA): Fluid management**

Receiving fluids via IV (intravenously) is common practice during medical procedures. For example, people receive fluids via IV during surgery, labour, and in medical emergencies.

#### **For people with FA and cardiomyopathy**

For people with cardiomyopathy, there are some factors which need to be taken into account when receiving fluids via IV. A heart that has cardiomyopathy is unable to tolerate fluids in the same way as a healthy heart, and this needs to be considered when receiving fluids. This is not to say that someone with cardiomyopathy cannot receive fluids via IV, but rather that the medical professional administering the fluids needs to be aware that the person has cardiomyopathy so that fluids can be given in an appropriate way. This might involve altering the speed that the fluid is given, or increasing monitoring of the heart during the procedure.

We suggest that before undergoing any planned procedure, those with cardiomyopathy should have a cardiac assessment, including a recent Echo (echocardiogram). This will allow the medical professionals involved in the procedure to plan accordingly, based on the results of a recent Echo.

*Therefore, it is important that before undergoing any medical procedure that involves receiving fluids, the medical professionals involved must be made aware of your cardiomyopathy diagnosis, and should consult with your cardiologist.*

#### **For people with FA and no diagnosis of cardiomyopathy**

For those with FA but with no cardiomyopathy diagnosis, some steps still need to be taken to ensure safe administering of fluids. It is possible that some small changes to the heart have occurred, which haven't necessarily resulted in a diagnosis of cardiomyopathy, but which still might change the way the heart responds to receiving fluids.

We suggest that before undergoing any planned procedure, those with FA should have a cardiac assessment, including a recent Echo (echocardiogram). An Echo is a test which helps to identify problems with the heart. People with FA are advised to have yearly cardiac assessments, so it would be considered sensible to also have an Echo in preparation for any procedure which involves the administration of fluids. This will allow the medical professionals involved in the procedure to plan accordingly, based on the results of a recent Echo.

*Therefore, it is important that before undergoing any medical procedure that involves receiving fluids, the medical professionals involved must be made aware of your FA diagnosis, and the effect FA can have on the heart, and should consult with your cardiologist or neurologist.*

#### **In emergency situations**

In an emergency situation, it is unlikely that there will be time for an Echo, and the person with FA might not have had a recent cardiac assessment. In this case, the medical professionals involved need to be made aware of your FA diagnosis (and cardiomyopathy diagnosis, if appropriate), as increased monitoring of the heart will need to be done during any procedure.

Ataxia UK recommends that people with FA carry this information regarding fluid management with them, in case of emergency.

**This information leaflet was written by Ataxia UK in collaboration with Prof Paola Giunti and Dr Michael Parkinson, Consultant Neurologists at the London Ataxia Centre at the National Hospital for Neurology and Neurosurgery (NHNN), and Dr Konstantinos Savvatis, Consultant Cardiologist at St. Bartholomew's Hospital.**

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