



Emergency care plan

Once you have established a relationship with your local care team it will be useful to sit down with your community nurse or consultant and devise an emergency care plan. This will help you and your care team to understand your wishes, in the event that a life-threatening illness should affect your child or loved one.

For example, you may feel that, should your child get an overwhelming chest infection which does not respond to antibiotics, you would then like nature to take its course. This may mean that your child or loved one will be kept comfortable and out of pain, but not treated with medicines aimed at curing the illness or getting rid of the infection.

After receiving a diagnosis of NP-C, L's family found themselves having to tell their story time and time again, and having to continually pester the appropriate authorities in order to convey L's need for essential care, equipment and services to assist her in daily living. The family was given the opportunity to create an emergency healthcare plan for L and life was transformed. Visits to the A&E department became easier, communication between the many professionals involved in L's care improved greatly, and she began to benefit from individual care and support that was delivered as her needs presented (not three months later!). The plan ensured that L's care was as seamless as possible and that all professionals – even those not involved on a regular basis – were aware of, and respected, the needs and wishes of L and her family.



Unless you have discussed an emergency care plan with your consultant, and you have agreed to this plan and put it in writing, your wishes may not be observed. If an ambulance takes your child/loved one to an A&E department then, unless this plan is in place, the medical staff may do everything in their power to save the person's life, including carrying out invasive ventilation, which may or may not be in accordance with your wishes.

Whatever decisions you come to, it is very important that everyone knows your wishes, in order that they can provide you with support at times of crisis. Remember – the plan can be reviewed or changed at any time, according to your wishes. Copies should be kept with the person, and also given to others caring for them.

This leaflet forms part of a resource pack published by the Niemann-Pick Disease Group (UK). It is intended to be read in conjunction with the other parts of the pack. If you do not have the other documents in the pack or you would like further information, please contact us at the email address below.

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