

## These are the coping strategies which KLS carers may find useful during episodes:

- A carer should be at home and available for young KLS sufferers and even older ones when needed
- Do not wake them up - except to try to encourage them to drink fluids if they are asleep for a very long time. If this is not possible and you are worried seek medical attention.
- Keep them at home as much as possible, they may appear at times to be feeling normal when in an episode, but will not be.
- Do not let them out alone since they will not be aware of danger crossing roads for example.
- Have nobody else in the home apart from immediate family/loved ones if possible.
- Be guided by moods.
- Watch food intake and make sure they do not become dehydrated. Help them drink with a straw if they are too tired to lift their head to drink. Offer them nutrition drinks if necessary if they are not waking to eat.
- Don't speak unless they want you to and then keep very quiet and calm and use simple words. They almost certainly will not be able to cope with answering questions.
- Be prepared to sit and watch the same films over and over again with them.
- Keep a diary - sometimes it helps to see what is happening and may be especially helpful if they do not have a diagnosis yet.
- When coming out of an episode be prepared for upset, frustration and anger.
- Try not to get frustrated and upset by the feelings of helplessness- we all find this one the hardest!
- Try not to worry....he/she will come out of an episode!
- When beginning to come out of episode, driving them for a short car journey may be a good idea to start getting them to feel they are returning to normal life.
- Be prepared that they may go into an episode at any time and have a plan with school or work.

In between episodes it is recommended that individuals with KLS have a regular sleep routine, avoid alcohol and contact with infectious people. It is useful to keep a sleep and symptom diary particularly before diagnosis.

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