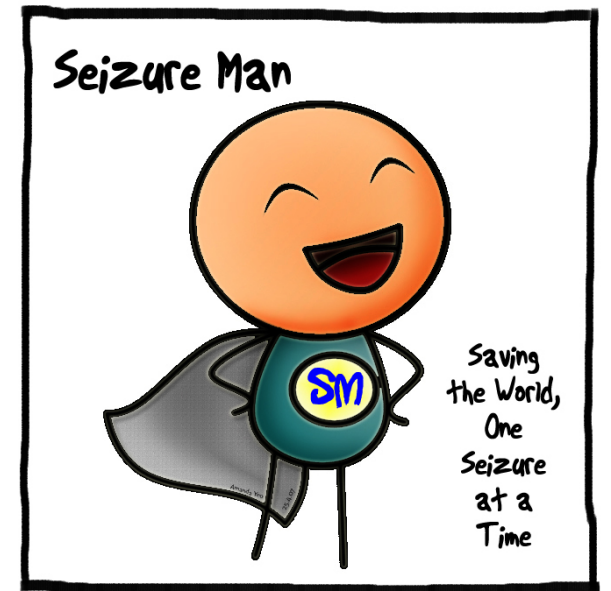


Frequently Asked Questions - Neil Williamson



Babies and Toddler's

- Why is my child having seizures?
- Will my child, Eat? Walk? What are the risks to their life?
- What do these letters mean?
- Everything else seems so normal?
- How do I feel ok sleeping at night?



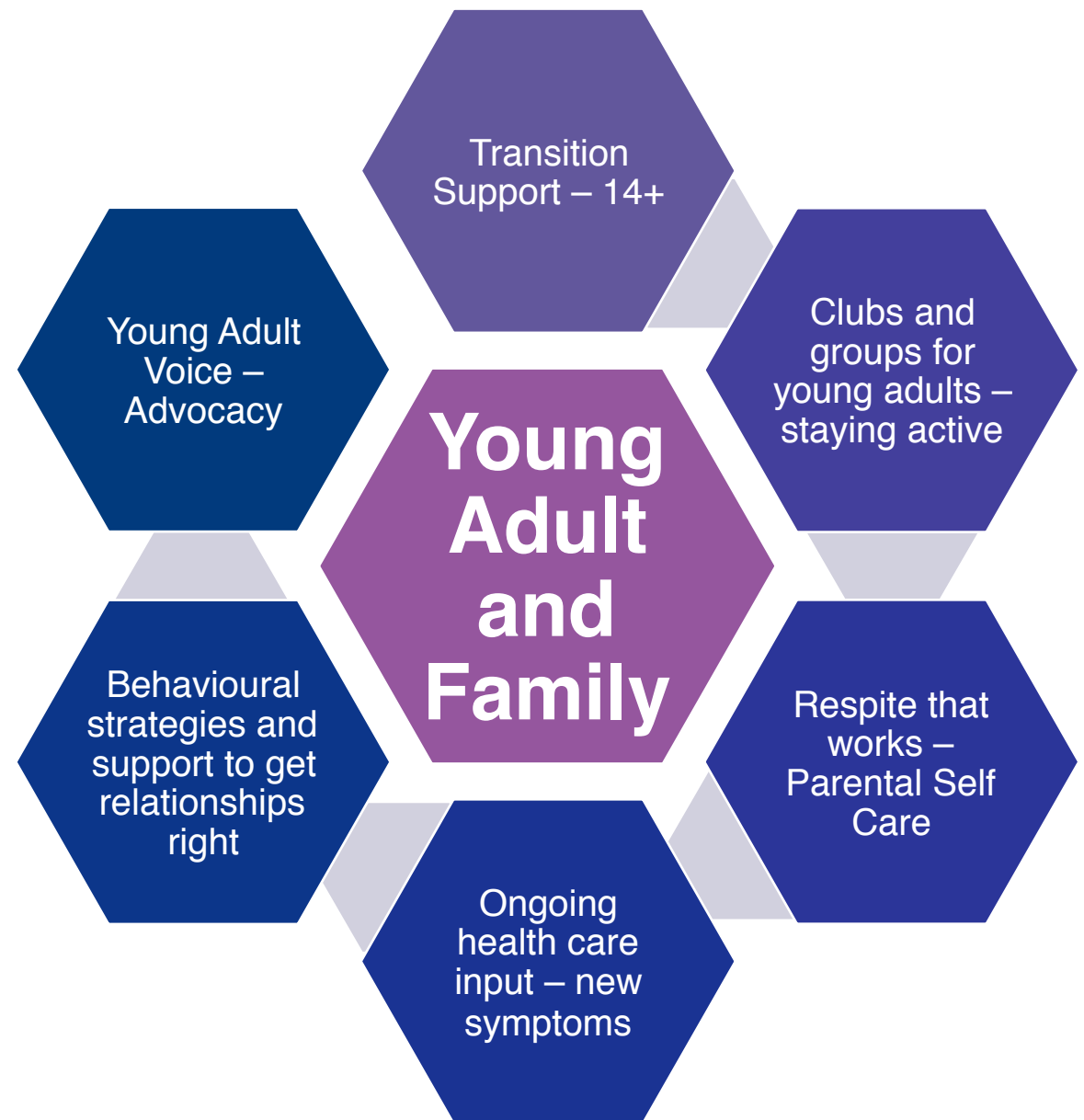
School aged children

- What school do I choose??
- How do I prioritise appointments?
Manage all the professionals?
- How do I train family members? How do I get/What is appropriate respite?
- **I am so tired** (more a statement than a question!!)
- How do I ensure my other children are ok?



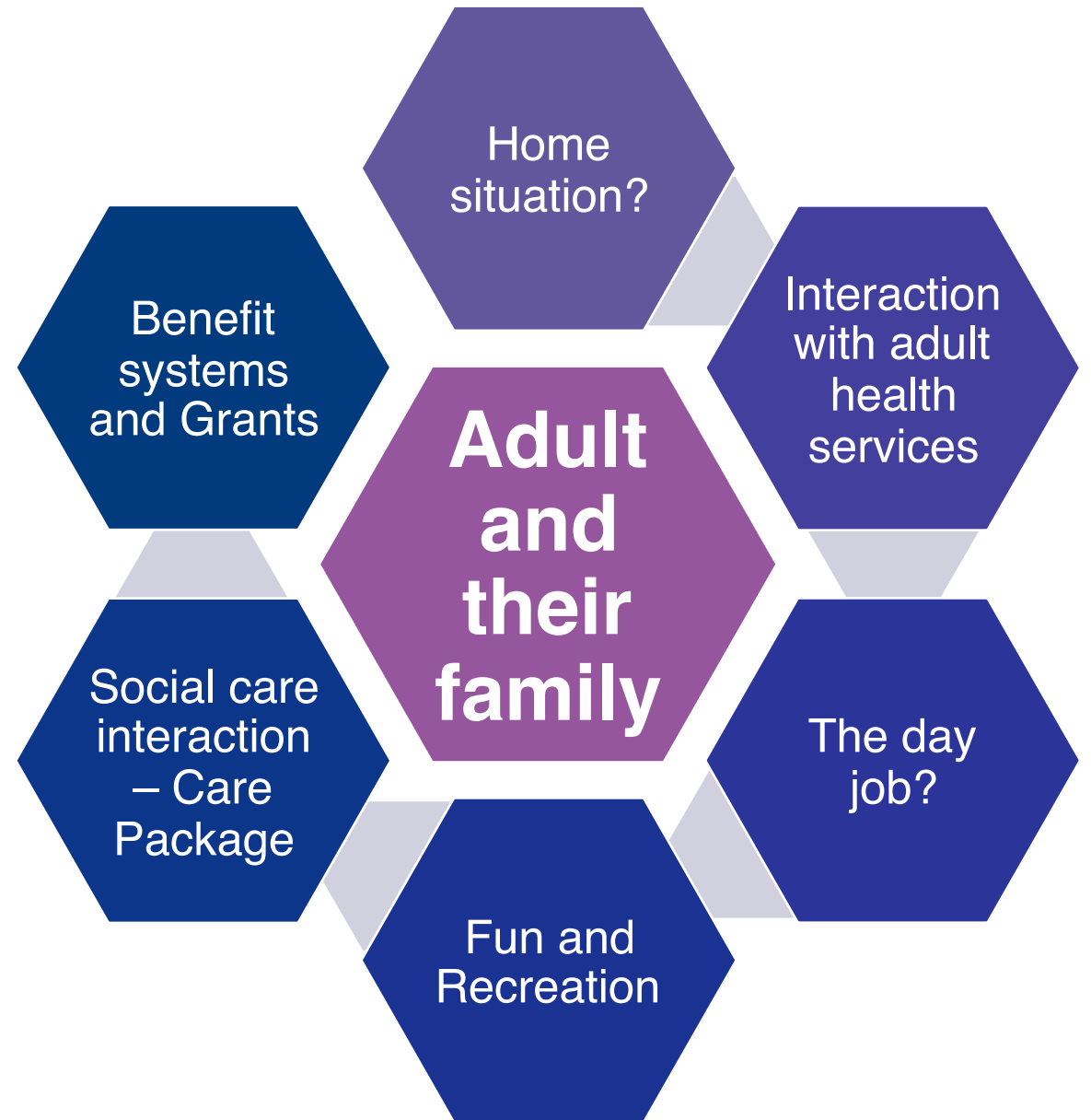
Young Adults

- What happens once my child is an Adult?
- How does Dravet syndrome affect adults?
- Is residential care an option?
- How do I get choices over my child's best interests when they cannot decide?
- How do I manage safety Vs Freedom?



Adults

- Who are the key people?
- How do I make sure this life is the best life?
- My child is an adult I need to have some time, how do I balance?
- How do I get the care we need?



Useful Links (1) - Grants

- <http://www.roalddahl.com/charity/family-grants/information-for-professionals/apply-for-a-grant/application-form> - Roald Dahl Family Grants
- <https://www.disability-grants.org/> - All sorts of grants
- <https://www.dravet.org.uk/families/get-support/> - Dravet UK grants
- <https://www.familyfund.org.uk/FAQs/are-we-eligible-to-apply> - Family Fund

Resources

- <https://www.dravet.org.uk/resources/> - Dravet Syndrome resources – including transition guide
- <https://www.dravetfoundation.org/registries/resources/> - US Dravet Association
- <https://www.youngepilepsy.org.uk/> - Young Epilepsy
- <https://www.epilepsy.org.uk/> - Epilepsy Action
- <https://www.epilepsysociety.org.uk/> - Epilepsy Society
- <https://www.childbereavementuk.org/> - Bereavement Support

Siblings / Groups

- Over The Wall – www.otw.org.uk – Sibling camps for children 8-17.
- Hope for Epilepsy London - <http://www.hopeforepilepsylondon.org.uk/>
- Carers UK - <https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/young-carers-and-carers-of-children-under-18> - Look for local carers groups in your local area

