



**PalliativeCare**  
AUSTRALIA

# PCA *Connect*

## The Diagnostic Odyssey of Genetic Diseases

### RESOURCES

*The resources below have been compiled to build on the learnings of this PCA webinar, and to provide the important support that was highlighted.*

#### Education for Clinicians

- [Communication about rare diseases](#)

#### Genetic Testing

Info for Families;

- [Receiving a Diagnosis – Rare Find Foundation](#)
- [SWAN Australia frequently asked questions](#)
- [SWAN genetic and genomic testing information](#)
- [Genetic and genomic testing](#)
- [Genetics A-Z Factsheet](#)

#### Parent Support

- [MyTime - Supporting parents and carers of children with disability](#)
- [Support For Your Family Overview](#)
- [Carer Gateway Counselling Service](#)
- [Genetic Conditions](#)
- [A-Z Support Directory](#)

#### Palliative Care Information

- [Palliative and end-of-life care – Rare Find Foundation](#)

#### Education and Schooling

- [SWAN Education information for parents](#)



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### **RESOURCES**

#### **Siblings**

##### Info For Parents

- [How to care information for parents and carers](#)
- [Coping Skills & More - Parents & Siblings | Siblings Australia](#)
- [Rare Find - Information for Families](#)

##### Sibling peer support

- [Livewire - connecting teens living with illness or disability, and their siblings](#)
- [Helping Children with Death and Grief Programs | Feel the Magic](#)

#### **Bereavement**

- [The Compassionate Friends Australia](#)

#### **NDIS**

- [SWAN resources on NDIS; fact sheets NDIS](#)

#### **Puberty**

- [SWAN Australia navigating puberty information](#)

#### **Practical**

- [Resources To Make Your Life Easier SWAN Australia](#)
- [SWAN telehealth patient pathways nurse](#)

*Thank you to SWAN Australia, the Rare Find Foundation, Rare Care Centre, and the Paediatric Palliative Care National Action Plan Project for your support and input.*