

## Position description

### Program Manager – Lived Experience

#### About the Childhood Dementia Initiative

The Childhood Dementia Initiative is driving world first action for every child with dementia. We are finding better ways to research, treat and care for the 70+ disorders that lead to childhood dementia. Through bold, innovative approaches and systemic change we are improving outcomes for children with dementia across the world.

**Our Purpose:** To transform research, care and quality of life for children with dementia so they may live long and fulfilling lives.

#### Our strategic pillars:

- **Advocacy and influence** - we are the voice of childhood dementia, reframing the conversation and ensuring we are heard wherever we can influence change.
- **Awareness and education** - we increase the general awareness of childhood dementia, while educating researchers, health professionals and families.
- **Facilitation and coordination** - we bring great minds together and unite voices to ensure greater efficiency, drive systemic changes in research and promote collaboration.
- **Organisational sustainability** - we build strong foundations in funding and governance.

#### Overview of the role

This newly created role will be responsible for leading our lived experience program ensuring that the voices of families are at the heart of everything that we do. The primary purpose of this role is to:

- work with families to support and enable their goals as childhood dementia advocates;
- amplify the voices of families;
- ensure that lived experience is embedded in policy and practice;
- coordinate consultation and codesign processes in partnership with external stakeholders.

<b>Reports to:</b>	Head of Programs – Care & Quality of Life
<b>Location:</b>	Sydney (preferable) - but flexible for the right skills & experience
<b>Status:</b>	Part time (0.4 FTE)
<b>Direct Reports:</b>	N/A
<b>Date Effective:</b>	Oct 2022

## Who are we looking for?

The successful person will have a tertiary qualification in a health sciences field (or similar) and significant professional experience working alongside families impacted by chronic and/or life limiting disease. Skilled, empathetic and passionate about our cause, the right person will have experience in appropriately representing lived experience in research, policy, practice or other projects. This role will require the skills and ability to build the Childhood Dementia Advocates Program and to work collaboratively with external partners (e.g. research teams) to ensure lived experience is appropriately integrated across projects that will ultimately impact treatments and care. Crucially, the Program Manager will champion the family voice at all times and will ensure that families feel safe, heard, understood and valued when sharing their experience.

### Desirable qualifications and experience:

- Tertiary qualifications in health, nursing, psychology, social work, counselling or related field;
- Experience in consumer participation, consultation and/or co-design in a health field;
- Demonstrated success communicating and collaborating with health professionals and research academics;
- Experience in recruiting and communicating with consumers/family advocates;
- Experience in the development of psychosocial and other research protocols where lived experience is key to success.

## We are a young and ambitious organisation, and have the personality to match

### How we work - we:

- consult and collaborate with families, service providers, health professionals and other partners;
- have the opportunity to build and embed the right systems and structures from the start;
- are pioneers with global ambitions to change the world for all children with dementia.

### We offer:

- flexibility – work days/hours, location;
- an ambitious and dynamic culture;
- genuine opportunity to create change.

## Next steps

To apply please send a cover letter and your resume to Gail Hilton, Head of Programs - Care & Quality of Life by 5pm, Friday 9th September - [gail@childhooddementia.org](mailto:gail@childhooddementia.org)