



**Li-Ve**  
TASMANIA

## *Li-Ve Ability*: Creating an inclusive culture at the end of life for people living with disability

*Li-Ve Ability* is a research-informed initiative aimed to create an inclusive and collaborative culture when providing end of life care for people living with disability.

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## Background for Li-Ve Tasmania

Li-Ve Tasmania has been established for over 65 years in Tasmania. In 2019 it supports over 200 individuals and employs 400 staff. Li-Ve Tasmania provide genuine person-centred support to people living with disability in Tasmania. The organisation's portfolio includes 17 group homes and a diverse range of community access programs, statewide. It supports participants of all ages with diverse support needs arising from a broad range of disability. Over the past 14 years, Li-Ve Tasmania has demonstrated particular expertise in services supporting people living with acquired brain injury and/or dementia.

In addition to its internal investment in maintaining services at an industry-leader level, Li-Ve Tasmania is highly committed to collaborating with like-minded industry leaders to achieve enhanced outcomes for people with disability at the end of life. It does this by:

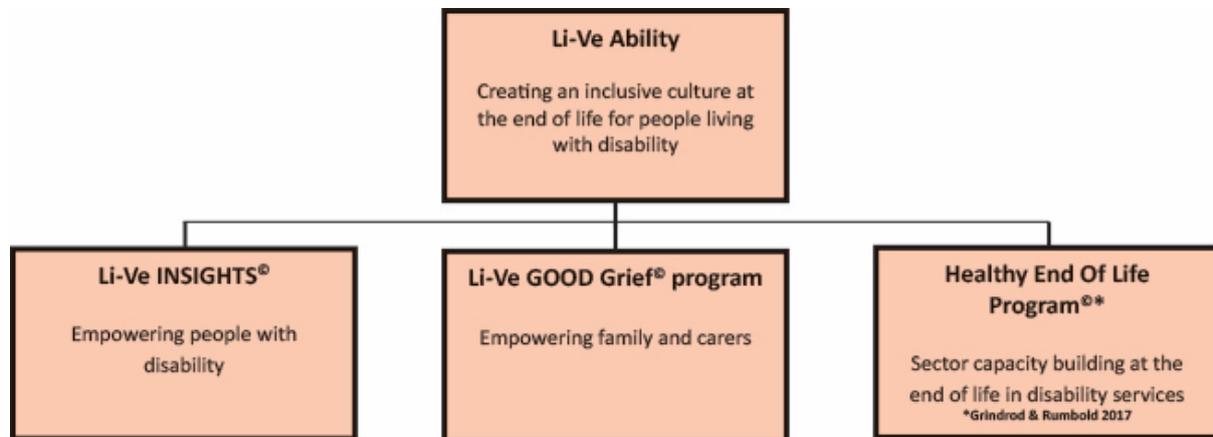
- Contributing its own practice-based wisdom to evidence-based research
- Providing quality education to people living with disability (and those who support them) regarding the end of life and bereavement,
- developing evidence-based resources in end of life care for people with life-limiting illness and disability.

In 2016, Li-Ve Tasmania gained extensive insight regarding the issues, barriers, opportunities and service gaps Tasmanians living with disability experienced at the end of life, within local palliative care and disability settings (Holliday, A. (2016) *Li-Ve Tasmania: Quality end of life care for people with disability, a Tasmanian perspective*, Tasmania, Australia). This knowledge has been pivotal, enabling Li-Ve Tasmania to enhance the opportunities for and experiences of people living with disability at the end of life. This enhancement has occurred in ways that influence individual and organisational capacity and capability, including community culture, systems and practices.

There is broad consensus that the end-of-life care offered to people with intellectual and/or cognitive disability, and other vulnerable populations, should be of a quality consistent with that advocated by contemporary palliative care. In practice, however, people with Intellectual or cognitive disability encounter various systemic barriers that result in the absence of choice and poor end-of-life outcomes, reflecting the inequitable life circumstances of living with a disability (Grindrod & Rumbold, 2017).

Li-Ve Tasmania prides itself in working in partnerships for the benefit of supporting people living with disability in all life stages, including the end of life. Li-Ve Tasmania has expertise as a leading service provider for people with disability on matters concerning the end of life, including bereavement at local, national and international levels.

Within the Tasmanian community, Li-Ve Tasmania currently leads a range of initiatives focused on enhancing end of life care and bereavement outcomes for people with disability, namely the **Li-Ve Ability** program.



The **Li-Ve Ability** program consists of three components:

**1. Recognition and value for the voice of lived experience: People with disability focus**

*This service area is aimed at generating social change that results in people with disability being recognised for their contributions to treatment planning and end-of-life care discussions, being appropriately supported in their experiences of grief and loss. It involves working collaboratively with people with disability to develop resources. Further, it empowers them to take leadership roles within their communities as champions of this topic. Li-Ve Tasmania's **INSIGHTS**® program is foundational in its approaches to education and awareness about the lived experiences of people with disability, including their experiences while living with life limiting illness, and adjusting to loss, grief and/or bereavement.*

**2. Strengthening informal support networks: A families and carers focus**

*To date, Li-Ve Tasmania's community consultation and analysis of services indicate that there are significant challenges for the families of people with disability who want to connect with existing (well-resourced and capable) support services, such as individual counselling, family counselling, peer support groups and individualised support programs. For the families (including siblings) of people with disability who are dying and/or bereaved, this strategy focuses on developing mechanisms to enhance support services and also the connections to these services. It also focuses on strengthening the roles and relationships between families and carers, and their loved ones. Li-Ve Tasmania's **GOOD Grief**® program enables families, carers and other supporters to confidently include their loved ones living with disability in conversations about the end of life and bereavement.*

### 3. Building capacity and capability in our community: A Disability and community sector focus

Li-Ve Tasmania actively engages and nurtures relationships with an extensive and diverse range of community stakeholders to work together to ensure that *all* Tasmanians have access to high quality, co-ordinated, respectful palliative care that is person-focused and includes support for families and carers. The focus of these partnerships continues to be on building capable and confident communities of care and the results to date, have demonstrated significant and sustainable changes within the Tasmania service system for people with disability.

Li-Ve Tasmania has recognised and acted on the need for a public health approach to palliative care and bereavement for people with disability in Tasmania, and sought a partnership with La Trobe University's Healthy End of Life Program (HELP) to guide an evidence-based and research-informed approach.

It created, administers and manages a **Disability End of Life Community of Practice** to support sustainable outcomes and maintain currency with best practice care. This forum enjoys membership from a broad range of disability-specific and generic community services.

In addition, Li-Ve Tasmania has led a study of a sector capacity and capability building project, the *Li-Ve Healthy End of Life Program*: A research collaboration between Li-Ve Tasmania, University of Tasmania and Latrobe University Palliative Care Unit. The first of its kind in Australia, this Study (outlined in further detail within this paper) considers the Healthy End of Life Program (HELP) amidst a suite of organisational support strategies. These strategies include experiences, tools and expert coaching tailored for an organisation and designed specifically to guide organisations to embed a healthy approach to the end of life care for the people they support. *Li-Ve Healthy End of Life Program* will ultimately improve the way people with disability experience the end of life.

Li-Ve Tasmania has extensive experience working collaboratively with others and is proud to have a secure profile as a leading service provider for people with disability in the end-of-life care domain on local, national and international levels.

## The Li-Ve Healthy End of Life Program Research

Using a public health framework to palliative care (Kellehear, 2005), *Li-Ve Healthy End of Life Program* applies the evidence-based organisational capacity building ‘Healthy End of Life Program’ (Grindrod & Rumbold, 2017) within a comprehensive sector development approach to measure its utility in building capacity and capability to improve the end of life experiences of people living with a disability.

*Li-Ve Healthy End of Life Program* focuses on enhancing disability service organisational systems, culture and practice to embed a healthy end of life approach for people living with disability.

Li-Ve Tasmania, University of Tasmania & Latrobe University Palliative Care Unit are proud partners for the *Li-Ve Healthy End of Life Program* study.



### Design

All participants of the *Li-Ve Healthy End of Life Program* study are currently employed to provide residential support to people with disability in Tasmania.

The study will be implemented across four sites, each receiving:

1. **A pre-study briefing** to the organisations leaders (including representatives from the organisation’s governance group, Human Resources, operations portfolio and other leaders). The purpose of this session is to provide background information on the HELP model (in the Tasmanian context), the aims and objectives of the study and participant requirements.
2. **One full day workshop** dedicated to providing information, education and resources to assist each organisation to enhance its understanding of: the end of life, the palliative approach and the Healthy End of Life Program (HELP) model. Participants of the workshop represent a cross-section of roles and responsibilities within each organisation.
3. Participants will complete a **pre and post workshop evaluation** survey to capture insights regarding the value of: the program content, presentation methods and session outcomes. This evaluation mainly aims to assess individuals’ confidence and perceived capacity to deliver healthy end of life outcomes for the people they support.

4. **One ‘Practical Tools’ session** held for each organisation within one month following the delivery of the Workshop. Content will include relevant community service contact lists, flowcharts describing access to palliative care services and HELP Asset Mapping resources to assist organisations to locate and engage with relevant community-based supports for people with disability they support at the end of their lives.
5. One follow-up **semi-structured interview** with selected representatives of each organisation to examine participant experiences during the pilot, and an opportunity to identify and commit to resolving any anticipated barriers to embedding the learnings from the pilot into organisational strategies, culture and practices.
6. Following the study, an offer for one representative from each participating organisation, to join the **Li-Ve Tasmania Disability End of Life Community of Practice** to support sustainable outcomes and maintain currency with best practice care.
7. Six and twelve months after receiving intensive support (briefing, workshop and follow up practice visit), all participants from each organisation will be invited to complete **second and third evaluations** to assess any sustained impact of the pilot and measure any benefit to people with disability.
8. Throughout the period of the study, each organisation will receive **coaching** to support the organisational development process. This will help consolidate organisational understanding of the principles and application of the Healthy End of Life Program model.

### **Data collection**

*Li-Ve Healthy End of Life Program* explores the application of an evidence-based sector capacity building framework (Healthy End of Life Program) and organisational development model for implementation. It describes and measures any resulting change to organisational capability and capacity to achieve sustainable, systemic improvements to end of life care for people with disability as a result of participation.

Specifically, *Li-Ve Healthy End of Life Program* examines how the five key domains of the Healthy End of Life Program outlined below, influences the capacity and capability of disability support organisations to enhance systems, culture and practice in relation to their ability to:

1. Align policy and protocol with practice
2. lead on social dimensions of dying
3. build on service assets and existing practice
4. develop staff capability and service capacity
5. embed healthy approaches to the End of Life and Bereavement.

*Li-Ve Healthy End of Life Program* also measures the value and capacity of existing tools and resources to achieve improved outcomes for people with disability at the end of their life.

This study is collecting data from a range of sources to develop a response to the set of research questions and evaluate the outcomes. This includes interval surveys, semi-structured interviews and case studies.

### **Analysis**

Quantitative and qualitative data is being collected and analysed with standard analytical techniques and/or thematically analysed using standardised software.

The study draws upon evidence based measures for capacity building within each participant organisation. This process will determine whether capacity has been enhanced as a direct result of participation in the study and whether this capacity has led to improved end of life care outcomes for people with disability.

### **Summary**

Li-Ve Tasmania, University of Tasmania & Latrobe University Palliative Care Unit are proud partners for the Study of *Li-Ve Healthy End of Life Program*. Early evidence from case studies and participant reports reveals positive indication of enhanced individual capacity and organisational, cultural and structural enhancements.

*Li-Ve Healthy End of Life Program* will report on formal study findings and research outcomes. In particular, it will address the ways in which the implemented model influenced the structures, culture and practices of disability organisations as they support people with disability at the end of life.

For more information about the study *Li-Ve Healthy End of Life Program*: sector capacity building at the end of life in disability services please contact:

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