Victorian Disability and Palliative Care

‘Strengthening our Work Together’

16th May 2024, Forum Report

Introduction

People living with a disability face additional challenges in terms of accessibility that could restrict or delay their access to timely palliative care services. In fact, existing research demonstrates that people with a disability are less likely to receive palliative care than people without disabilities. In response to this, National Disability Services, Nightlife Disability Services, North and West Metropolitan Region Palliative Care Consortium, and the North Western Melbourne Primary Health Network formed a working group to coordinate a face-to-face forum to be held on 16 May 2024 at the Melbourne Convention and Exhibition Centre. This was for disability, palliative care, and other key stakeholders to meet and discuss how access to end of life planning and supports including palliative care could be improved across the service sectors.

The Hon. Ged Kearney, MP, Assistant Minister for Health, and Aged Care opened the forum with a recorded message.

The initial idea was to host a small event for 50-70 representatives with a small working group of disability and palliative care key stakeholders offering time and expertise to facilitate forum planning. Increasing interest in the forum resulted in a decision to increase attendance capacity to 200 and this was enabled by additional seed funding support from the following organisations: Barwon South Western Region Palliative Care Consortium, Gippsland Region Palliative Care Consortium, Grampians Region Palliative Care Consortium , Hume Region Palliative Care Consortium, Loddon Mallee Regional Palliative Care Consortium and Southern Metropolitan Region Palliative Care Consortium .

Additional organisations contributing to the forum with back of house planning, resources and time included: Palliative Care Victoria, Melba Disability Support Services, and Motor Neurone Disease Victoria.

genU Disability Services in addition to participating in the Working Group provided all speakers with The Otway Kitchen homemade relish and sauce gift packs produced through their social enterprise division. Murry Payne from Centreforce creative digital solutions offered his support for the event through video and photography to capture this special event for all involved. The photos used throughout this report are reflective of this contribution.

The forum sold out with 90 participants from the disability sector, 49 from the palliative care sector, 33 from the health sector, 11 from government agencies, 4 university representatives and 8 other key stakeholders including 3 speakers with lived experience. These figures suggest the event garnered interest across all these sectors and provided opportunities for discussion and collaboration around an issue of cross-sector importance.

Forum outcomes

The Working Group intended the forum would be the start of a further conversations and actions in support of increasing access to end of life choices and supports for people with a disability. The two overarching themes arising from the discussion and feedback reflect the interest in further engagement. These were:

- the need for the conversation about end-of-life choices and supports for people with a disability to continue and be openly embraced by all stakeholders to enable existing access and equity barriers to be addressed
- the importance of a collaborative approach with the expertise and leadership of people with a lived experience of disability to inform next steps with key stakeholders.

The document below outlines the collaborative planning process, program content, wellbeing supports, discussion themes and actions proposed for next steps for consideration by the Victorian Disability and Palliative Care Advisory Group. Feedback quotes have also been included in the text boxes and reflect the majority response themes.

> ‘This is a very important and much ignored area, and the beginning of these discussions is very exciting.’
>
> ‘It was a great forum. Very thought provoking, good variety. Only thing I can suggest would be to have a bigger forum over two days or to hold more forums on disability and palliative care. Really interesting day, thank you.’

Program content

The day aimed to initiate discussion about disability and palliative care within the Victorian context. It included the perspectives of people involved in delivering disability services, palliative care support, peak bodies, and direct care workers. The Working Group took a collaborative approach to identify speakers and panel members who would reflect on the knowledge and skill needs across their respective sectors; disability, health, and palliative care that could be improved through stronger connections with each other and people with a disability. Speakers and panels were also requested to highlight opportunities where improvements could occur regarding understanding of each other’s systems, practical implementation of end-of-life care in disability settings and increasing end of life health literacy regarding supporting someone with a disability.

The Hon. Ged Kearney, MP, Assistant Minister for Health, and Aged Care provided an encouraging recorded message highlighting the importance of the conversation. The message was recorded as it was a parliament sitting week. Funding support provided through the Northwestern Melbourne Primary Health Network enabled the engagement of broadcaster and writer Jacinta Parsons to moderate the forum program. Speakers in the program included disability providers, palliative care teams, Coroners Court representatives, Disability Liaison Officers, and other expert consultants.

Jacinta Parsons, broadcaster, and writer moderated the forum program maximizing the time available and opportunities for questions from the conference attendees.

Speakers with an identified lived experience of disability were approached for their interest in providing input. Despite the sensitive nature of the topic, all who were approached agreed to participate in the day to support increased discussion of grief, loss, life limiting illness and the rights to choose and control regarding planning for end-of-life needs.

All speakers and the moderator were invited to meet the Working Group in a pre-forum workshop to review the program content to reduce duplicated input. The workshop was incredibly positive with open and honest conversation about the information to be shared, aspects to highlight. Discussion of the level of involvement of people with lived experience highlighted the challenges of balancing input from a diverse range of perspectives. A reflection on the use of the term ‘case study’ identified this as a distressing term opened deeper conversation. As a result, the program was amended to ‘story’ out of respect for the conversation learnings and to model greater sensitivity to people with a disability. The open and honest discussion served to establish a strong and caring group of people who looked forward to working together and to support the speakers who were feeling less confident about taking a role in sharing a presentation to such a large audience. This process also enabled continuous learning by all involved.

‘Wonderful to hear the voices of people with lived experience and the passionate guest speakers.’

‘It was very informative and gave me insight into what our participants might face while going through this tough time.’

‘The coroner information was really interesting as was lived experience – great speakers.’

Left to right: Gabrielle Brennen, genU, Ashley Vickers, Nightlife Disability Services, Gillian Hilton, Disability Liaison Officer Program Department of Health Victoria, Samantha Moorhouse, Seymour Health, and Jacinta Parsons.

Program content included use of individual stories to highlight where barriers encountered by people with a disability and life limiting illness in relation to identification of needs, linkages with palliative care teams for discussion of supports, planning options and examples of end-of-life experiences that were not optimal. The barriers were explored from the lens of disability, palliative care, and health sectors. System impacts included an overview of the disability providers context and to highlight for health and palliative care the complexities of delivering support with a person receiving NDIS funding and how the systems to link with health are not straightforward and can result in barriers and gaps in the options for care.

Presentations from the Victorian Coroners Court included an overview of the death reporting requirements and the role of the police investigators. The presentation aimed to demystify the process and highlight the role of the coroner in identifying learning opportunities. The importance of gathering as much information as possible about the death of a person with a disability was highlighted when service providers (disability, palliative care, or health) engage in their care .

Left to right: Mary Henley-Collopy, Lived Experience Consultant Heather McMinn, National Disability Services Victoria, Uli Cartright, Lived Experience Consultant - Life is a Battlefield

Low levels of end-of-life planning and support, grief, and loss health literacy by workers within disability settings was explored by the speakers with lived experience. These speakers shared openly about living with grief and loss and the deaths of numerous close friends in the disability community. They noted how workers' avoidance of this conversation was a denial of their reality and right to access to end-of-life care information and choices available to other people. It was also recognised by other forum speakers that among the barriers to equitable access to end-of-life information and planning supports is a lack of confidence by many people, including disability workers, to talk about death and dying challenging all who attended to bring this conversation into the open to demystify and encourage the community to view death as part of life.

Refer to Appendix 1: Program

Janet McLeod, Melba Support Services

Forum supports

Wellbeing support

The wellbeing of forum participants was an important consideration of the Working Group and as a result two Palliative care representatives were available for any person who found the content distressing or triggering.

The palliative care representatives who provided wellbeing were identified for all participants during the welcome along with an invitation to all participants to embrace the day of discussion and learning from the perspective of care and support for each other. These wellbeing supporters were given unique coloured lanyards to enable easy identification for anyone who needed them. Working Group members were also asked to alert wellbeing supporters to check-in with individuals who appeared to be distressed. A wellbeing handout was available with contact details for a few key mental health and wellbeing organisations for any individuals if needed.

Refer to Appendix 2: Wellbeing support options

Sensory table

Another wellbeing initiative identified by the Working Group was the inclusion of a sensory table space within the forum's plenary room. The intent of including this sensory table was to offer an opportunity for any participant to access the tools for their own self soothing needs and to model self-soothing tools and resources for use by forum participants in their own work settings.

The table was set up with a variety of sensory items that people could self-select from. They were labelled by senses; smell, touch, visual and touch, vision, and taste, with guidance given on the use of these for forum participants.

The table was very popular and although its purpose was to assist anyone who was distressed on the day; the main feedback was that it enabled rich discussion on how you use sensory items as part of practice. Many attendees reported they had not seen sensory items used before, and they asked questions on purchase and use. There were comments that sensory work has not been widely used in palliative environments. This was surprising given extensive use in planning of cancer units (Olivia Newton John), the Royal Children's and aged mental health services (advanced dementia and Alzheimer's). A copy of a sensory assessment sourced from Queensland Health was also provided as a resource.

Refer to Appendix 3: Sensory table items

Motor Neurone Disease Expo Stand

Information and resources

Forum participants were also offered opportunities to discuss with expo stall holders their resources and training options. The expo organisation weblinks are included below for further information regarding resources, information, and training options.

Palliative Care Victoria - Easy English Resources

PEPA education, training and learning guides

Healthy End of Life Project (HELP) developed by La Trobe University

Motor Neurone Disease Victoria

Primary Health Networks Training and information support for General Practice

Disability and Palliative Care Resource

NDS launched the Palliative Care, life limiting illness, and support for people with a disability webpage at the end of the forum. This was developed in response to the Victorian Disability and Palliative Care Advisory Group and broader disability sector requests for a resource and platform for shared information, training, and resources. The web page was launched as a starting point for interested stakeholders across palliative care, disability, health sector and people with lived experience or carers to share with NDS evidence-based resources or information that can be added to support ongoing learning for all involved.

Discussion and feedback

Responses from forum representatives from across the multiple sectors indicated they are often not discussing health related choices and supports associated with death and dying with a person with a disability. They indicated this was often due to fear of causing distress and as a result avoided the topic altogether. This highlighted the ongoing need for more in depth learning and discussion opportunities for disability workers, health, and palliative care professionals to improve confidence and capability across the sectors to initiate appropriate conversations with resources and information applicable to the person with a disability, family, and carers. Ability to be sensitive to accessibility needs, cultural and spiritual traditions were also recognised as part of this capability need.

Karen Kessner, North and West Metropolitan Region Palliative Care Consortium.

> ‘I wanted to take this opportunity to extend my gratitude and joy at how amazing this day was yesterday. I wanted to congratulate you and your team on creating this really significant and beneficial event – well done. I would love to see this become an annual occurrence.’
>
> ‘You could tell how engaged the audience was as very few left at the afternoon tea break time.’

Palliative care sector participants also noted a need to develop stronger links with disability providers and people with lived experience. Other comments highlighted the need for more grief support for families, better communication between hospital staff and the disability sector, and understanding of the complexities of supporting people to die at home.

Challenges identified throughout the day that reduce access to palliative care for people living with a disability included not enough staff, inflexible organisation, and funding policies, with the NDIS funding model limiting disability worker training to core NDIS modules. This was highlighted in a panel discussion including a direct care disability worker who noted the impact on workers was distress - when they want to support people with a disability to die in their homes with appropriate supports but are trying to deliver this without access to the needed training to increase knowledge and skills. This limitation on training was noted throughout the day particularly in comparison to the standard of other sectors such as Aged Care or Health. Exploring how this capability increase could be achieved within current funding models was highlighted as a consideration for next steps. System barriers in health, disability and the NDIS processes were also noted as tensions to be further explored.

Presentations from people with lived experience challenged the stakeholders from all sectors to keep the conversation going to increase access to information about death and dying for a person with a disability. Representatives from across government, disability, health, and palliative care identified they wanted to keep learning and continue exploring cross sector collaborations that could improve this time of life for individuals, their workers, family, carer's and learning about bereavement supports for household residents and workers.

John McKenna, Lived Experience Consultant, Better Access Consulting - Better Access Consultinghttps://johnmckenna.com.au/

Conclusion

The resounding end of day comments were that it was time for this discussion and thankfulness to the Working Group for initiating the forum. Feedback forms revealed a high level of satisfaction with the event, with the average satisfaction rating being 4 out of 4. Most participants expressed that they strongly agreed with the content, the program format was appropriate and the information relevant to their role with indications that people left the event with knowledge and connections to use in their work moving forward. While some feedback suggested minor amendments to the forum program and length of different sections these were largely reflective of participant interest in engaging with the question-and-answer time and the limitations on this.

Left to right: Violet Platt, Palliative Care Victoria, and Jacinta Parsons.

Since the event additional feedback has been received by the forum Working Group organisations and many of the speakers who have all indicated strong interest in follow up actions to progress the conversation through specific events, webinars, shared resources, information, and additional forum opportunities. While this event was specifically targeted disability, health, palliative care, and other key stakeholder managers future events would expand for collaboration with wider audiences including more people with lived experience, family, carers, direct care workers and any other interested stakeholders.

> ‘It was such a privilege to be in the room today, the lived experience so generously shared with the audience as well as the sector experts and their valuable insights, gives me hope that by continuing the conversation we can create meaningful change!’
>
> ‘One of the best events I have been to!’

Key takeaways

Two overarching takeaway themes summarise the forum discussion and serve as foundations to addressing the specific gaps and barriers identified and how the proposed suggestions for next steps can be approached.

These themes are:

- the need for the conversation about end-of-life choices and supports for people with a disability to continue and be openly embraced by all stakeholders to enable existing access and equity barriers to be addressed

- the importance of a collaborative approach with the expertise and leadership of people with a lived experience of disability to inform next steps with key stakeholders.

Left to Right: Nadia Garcia, Yooralla and Jane Turton, Motor Neurone Disease and Parkinson's Disease.

Next steps

Discussion during the event and through evaluation responses indicated the need for further knowledge of disability by health and palliative care workers and of life limiting illness, death, dying, and bereavement for the disability sector. Addressing these improvements were identified as fundamental to building cross sector capabilities to increase access to information and choices related to life limiting illness with people with a disability.

Opportunities to explore in greater detail the specific barriers and improvement opportunities included suggested topics for sessions and resource sharing. These are captured below.

- Cross sector opportunities between disability support workers; and specialist palliative care providers to increase an understanding of each other, their roles and how they can work together with a person with a disability in relation to end of life information, support choices and end of life plans.

- Deeper dive into reporting process and requirements for the Victorian Coroner regarding the death of a person with a disability and implications if the death was expected as part of a palliative care process.

- Medication needs and administration within the disability setting for a person with life limiting illness.

- Advanced care planning end of life goals of care covering accessible formats, how to develop with a person with a disability and implement to support care decisions when needed.
- Discussion and understanding of grief and loss for people with a disability across the lifespan and not just related to end of life by key stakeholders.
- Identification of resources and supports for disability workers on death, dying and grief related to a person with a disability who has died.
- Identification of resources and supports on death, dying and grief for people with a disability that can be offered to individuals or to inform conversation s lead by family, carers, disability, or palliative care workers.

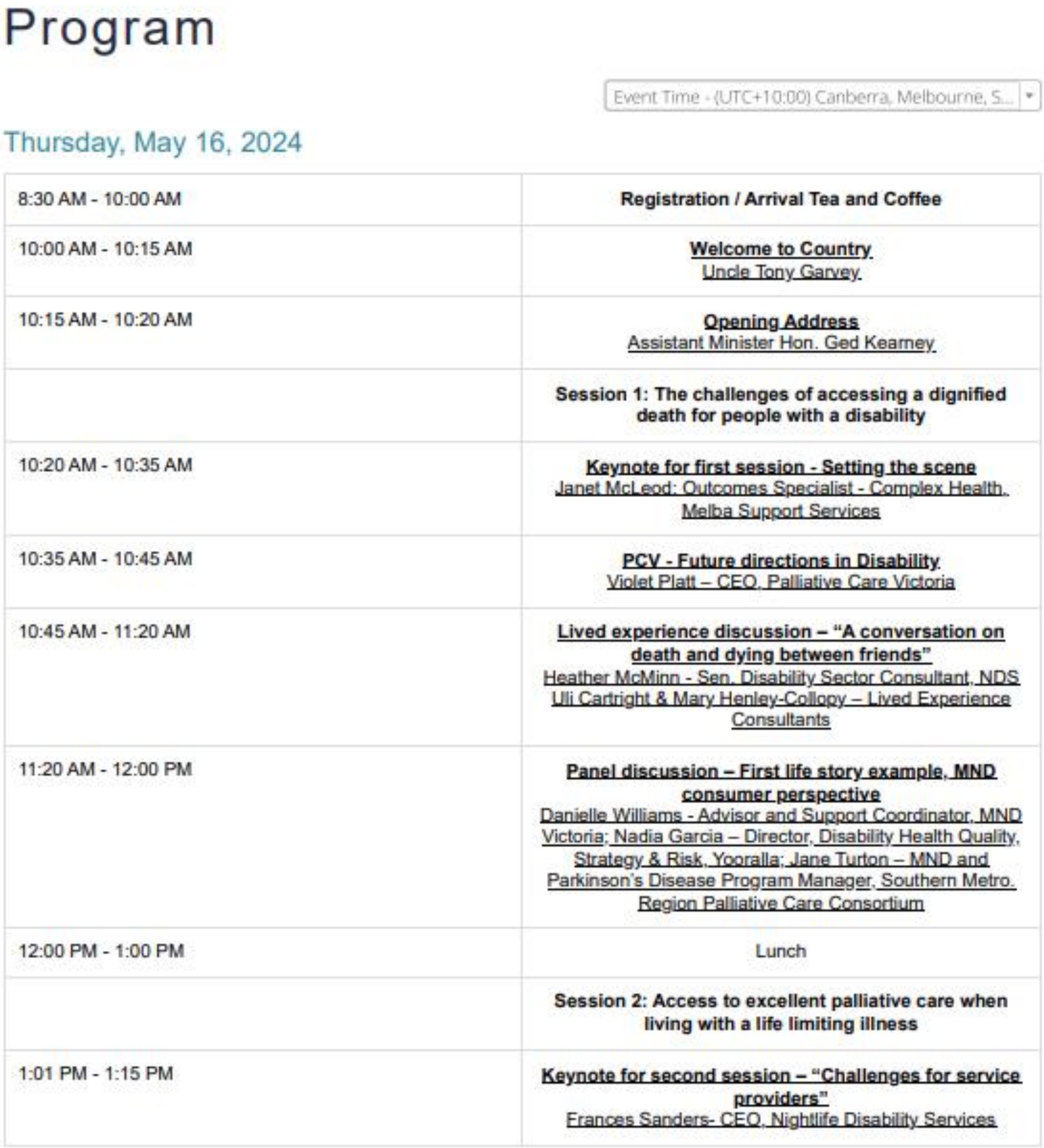
Additional areas for consideration as next steps focus on systems and require relevant key stakeholders to review together to address the barriers identified.

- Discussion and identification of models of capacity building with disability workers that could be implemented within the NDIS funding model that limits training flexibility.
- Improving communication between all key stakeholders to support person centred needs (ACP’s/Goals of Care and person-centred health plans or passports) during life limiting illness care including end of life stages.
- Improving communication in hospital settings to include disability workers who are delivering in home support or residential accommodation to ensure a person with a disability and life limiting illness can be discharged home with the appropriate supports in place.
- Increased opportunities for shared information (resources and policies) across health, palliative care, and disability sector to consistency in advocacy for change regarding supporting clients and workers.
- Exploration with NDIA regarding the support rules and requirements intersecting with health to increase access to palliative care in home and residential accommodation supports for a person with a life limiting illness.

- Discussion of the needs of people who are under 65 years of age with a life-limiting illness who don't qualify for the NDIS but have nowhere to receive in-home supports and end up in hospital for end-of-life care.

Frances Sanders,
Nightlife Disability
Services

Appendix 1:



Program

Thursday, May 16, 2024

8:30 AM - 10:00 AM	**Registration / Arrival Tea and Coffee**
10:00 AM - 10:15 AM	**Welcome to Country** Uncle Tony Garvey
10:15 AM - 10:20 AM	**Opening Address** Assistant Minister Hon. Ged Kearney
	Session 1: The challenges of accessing a dignified death for people with a disability
10:20 AM - 10:35 AM	**Keynote for first session - Setting the scene** Janet McLeod: Outcomes Specialist - Complex Health, Melba Support Services
10:35 AM - 10:45 AM	**PCV - Future directions in Disability** Violet Platt – CEO, Palliative Care Victoria
10:45 AM - 11:20 AM	**Lived experience discussion – "A conversation on death and dying between friends"** Heather McMinn - Sen. Disability Sector Consultant, NDS Uli Cartright & Mary Henley-Collopy – Lived Experience Consultants
11:20 AM - 12:00 PM	**Panel discussion – First life story example, MND consumer perspective** Danielle Williams - Advisor and Support Coordinator, MND Victoria; Nadia Garcia – Director, Disability Health Quality, Strategy & Risk, Yooralla; Jane Turton – MND and Parkinson's Disease Program Manager, Southern Metro. Region Palliative Care Consortium
12:00 PM - 1:00 PM	Lunch
	Session 2: Access to excellent palliative care when living with a life limiting illness
1:01 PM - 1:15 PM	**Keynote for second session – "Challenges for service providers"** Frances Sanders- CEO, Nightlife Disability Services

1:15 PM - 1:30 PM	**Community Palliative Care - Palliative care trajectories and the role of CPC** Sam Moorhouse – Clinical Nurse Specialist, Seymour Health
1:30 PM - 2:00 PM	**Introduction to the Coroner's Court** Laura McDonough - Law Institute Accredited Specialist and Director Legal Services with co-presenter Sgt. Ross Treverton
2:00 PM - 2:40 PM	**Panel discussion – Second life story example, supporting the DSW journey** Ashley Vickers – Disability Support Worker, Nightlife Disability Services; Gabrielle Brennan – Clinical Nurse Consultant, GenU; Sam Moorhouse – Clinical Nurse Specialist, Seymour Health; Gillean Hilton – Sector Coordinator – Disability Liaison Officer Program
2:40 PM - 3:15 PM	Afternoon Tea
	Session 3: Where to from here?
3:15 PM - 3:50 PM	**Panel Discussion - What happens next?** John McKenna who has a living experience of physical disability; Professionally, John is an empowerment advocate who has his own consulting practice; Frances Sanders - CEO, Nightlife Disability Services; Violet Platt - CEO, Palliative Care Victoria; Samantha Dooley - Melba Support Services, Project Officer - Quality and safeguarding in disability services
3:50 PM - 4:00 PM	**NDS resource platform launch and close** Heather McMinn - Sen. Disability Sector Consultant, NDS

Appendix 2:

Handout: Wellbeing Support Options

Lifeline

Lifeline provides short-term, confidential one-to-one support for people who are feeling overwhelmed or having difficulty coping or staying safe.
Call: 13 11 14 or 0477 131 11.

Griefline Australia

Need Support?

If you need help coping with grief or would like to support someone you care about experiencing loss and grief, you can connect with a number of free services below.

1300 845 745

National Helpline

Speak to a specially trained telephone support volunteer 8am to 8pm 7 days a week (AEST/AEDT).

Request a call back

Free grief support call

Schedule a 30-minute call with a specially trained Griefline telephone support volunteer.

Online forums

24/7 forums

Our online forums are a space for you to express and explore your grief with others in a peer-lead environment.

Griefline is not a crisis- support or emergency support service

If you are in an emergency situation or are at immediate risk of harming yourself or others please call 000. If you are experiencing crisis or are worried about yourself or someone else please call Lifeline - contact details above.

Kids Helpline is available 24/7 to support young people aged between 5 and 25 years. Call 1800 551 800.

Carer Gateway Carer Support Australia

Carer Gateway: Call 1800 422 737.

The new nationwide network of Carer Gateway service providers delivers a range of support services to unpaid carers, such as:

- In-person and phone-based counselling
- Online self-guided coaching
- Emergency and planned respite
- In-person and online peer support
- Online skills courses
- Financial packages focused on employment, education, respite, and transport.

Beyond Blue | 24/7 Support for Anxiety, Depression and Suicide Prevention

Talk or chat online to a counsellor

If you’re going through a hard time right now, the Beyond Blue Support Service is available 24/7 for brief counselling. Most calls last around 20 minutes.

Our counsellors will listen and help you find the extra mental health help you need.

Get free confidential counselling (local call costs apply).

Call a counsellor on 1300 22 46 36 or chat to a counsellor online.

Accessibility and language support are available for telephone counselling.

13yarn support for Aboriginal and Torres Strait Islander Community

If you, or someone you know, are feeling worried or no good, we encourage you to connect with 13YARN on 13 92 76 (24 hours/7 days) is for you, or someone you know who is feeling worried or no good.

Connect with and talk with an Aboriginal or Torres Strait Islander Crisis Supporter. This is your story; your journey and we will take the time to listen. No shame, no judgement, safe place to yarn. We are here for you.

Appendix 3:

Sensory Table Items - Nightlife Disability Services

Smell: essential oils and hand cream. Can be used for a hand massage with the act of opening oils, smell these and then using to engage senses away from distress.

Touch: variety of objects available to allow people to find their sensory preference
Hand held Massage – battery operated, active sensory preference.
Wooden massage roller – hand held – for natural sensory preference
Cool eye mask – could also be held and felt where cool items are preferred
Aloe Vera Wet wipes – cool and wet – wiping hands slowly engages in feeling
Heat pack – warmth and cuddly
Woolly cushion – warmth and cuddly – able to be squeezed
Sticky stretch bands – enabling play and engagement of hands

Visual and touch: items to encourage active play which engages multi senses
Squishy stress balls and caterpillar are traditional sensory items. They engage a person hands, and senses of feeling, texture, and vision.
Hand puzzle such as hard plastic. These can be played with (stretched / contracted) revealing different patterns.
Mandala's for people to draw and colour in. These assist with disengaging from intrusive thoughts.

Vision: A planet orb allowed different soothing colours and patterns.
This can also be activated to play to music.

Taste: Normally you would allow different tastes such as herbs
Jelly beans can be provided to enable people to think about their sensory preference to flavour and texture.

Resource: Queensland Health developed Sensory Preferences Checklist.
A copy of the checklist was provided for participants to takeaway.