

End of Life Care for People
with Alcohol and other Drug Problems
Research Project

'Insider Insights'



Amanda Clayson
Zac Sargent
2018

Introduction

The 'Insider Insights Digital Collection' is part of a suite of resources developed from a two-year exploratory study about end of life care for people with past or current alcohol and other drug problems. The study has five separate strands to it; looking at the existing evidence to extending new learning through talking with people with life limiting conditions and problematic substance use. This includes family members, friends and carers of people with both issues, and the professionals who work to support people in substance use and end of life care services. 'Insider Insights' is drawn from the work with people with a life limiting condition and their family members.

The Collection

Seven people from the wider group of participants within the research project gave permission for their interviews to be used to develop The Collection, all driven by the desire to improve the care and support available to people within similar circumstances to themselves. The contributors reflect a diversity of experience in relation to their history of substance use, the circumstances of the end of life, and the context of the care and support given and received across multiple settings.



Figure 1: Overview of voices heard within the Digital Collection

The Collection is made up of **12 curated clips** organised around four main themes. A complete list and links to all 12 titles is found on page four.

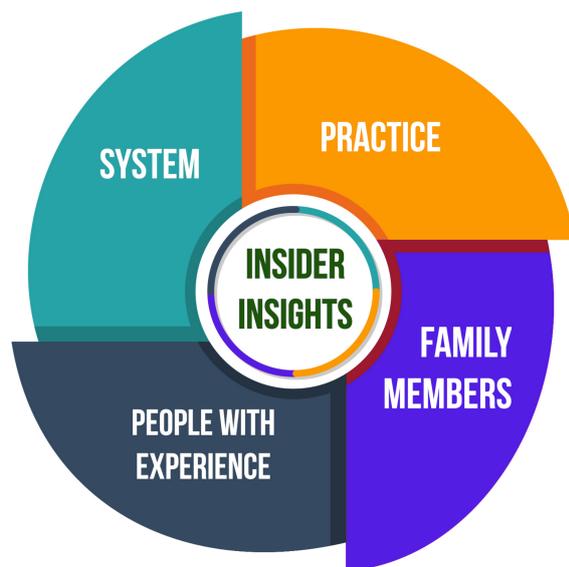


Figure 2: Insider Insight themes

- 1. People with experience**
Individual stories and personal impacts of care.
- 2. Family members**
Personal experiences of caring and support, before, during and after death.
- 3. Practice**
Messages for practitioners in specialist and non-specialist services across hospital, community and home.
- 4. System**
Policy and resource implications around substance use and end of life care across a range of settings.

The clips bring to life a range of issues shared by participants; some experiences were positive whilst others were less so. They do not cover every aspect of the research findings but do reflect many of the key messages expressed by the wider group of research participants.

Purpose

Listening to 'real and raw' voices share their experiences of care across a range of settings is powerful. Bringing to life the diversity of substance use and circumstances of their end of life is also very important, for the individuals themselves and for future care givers and policy makers. The Collection aims to maximise the value of participant interviews and broaden the reach, potential impact and influence that lived experiences bring to research and practice development. The clips have been designed to be used flexibly by a wide audience that may include practitioners, service and system developers, policy makers, researchers and students in various fields.



Thank you to everyone who shared their experience so openly and honestly

Find out more

A VoiceBox Inc Co-Production  BLFproject@mmu.ac

amanda@voiceboxinc.co.uk

A final note

This can be a difficult and emotive subject for many people, so be aware that viewers may need to take breaks or have support during or after viewing.

Access to project resources

www.endoflifesubstanceuse.com

Figure 3: 'Insider Insights' Digital Collection Titles and Links

| Focus | Overview of content | Length | Link |
|--|--|---------|---|
| Introduction | 01: A brief overview of the background and content of The Collection | 2m 20s | https://youtu.be/8WD2Y-N2pm4 |
| People with experience Individual stories and personal impacts of care. | 02: Common barriers to accessing information and support <ul style="list-style-type: none"> • Lack of information • Difficulty asking for help • Impact of needing support | 4 m 19s | https://youtu.be/z07HnznOldI |
| | 03: Some specific issues to consider <ul style="list-style-type: none"> • Struggles around medication • Feeling stigmatised and judged • Seeing beyond substance use 'behaviour' | 3 m 41s | https://youtu.be/KLeBvZnR02c |
| Family members, friends and carers Personal experiences of caring and support, before, during and after death. | 04: Some of the challenges families/carers experience in getting help <ul style="list-style-type: none"> • Impact of denial • Not thinking about themselves • Asking and receiving | 3m 12s | https://youtu.be/88sZ9HqUvNI |
| | 05: The emotional impact of caring <ul style="list-style-type: none"> • Responsibility and recrimination • Powerlessness and anger • Guilt and self-blame | 2m 57s | https://youtu.be/l_g0sugjCG8 |
| | 06: Grief and bereavement support <ul style="list-style-type: none"> • How grief is experienced • Does support help or hinder? • Moving beyond despair | 2m 49s | https://youtu.be/vKsNM0zBJNA |
| Practice Messages for practitioners in specialist and non-specialist services across hospital, community and home. | 07: Communication around 'end of life' – what helps and what doesn't? <ul style="list-style-type: none"> • Timely and direct • Interpretation and sensitivity • Involving and proactive | 3m 52s | https://youtu.be/LyQ18z2d3VE |
| | 08: Compassionate care is crucial <ul style="list-style-type: none"> • At home and in hospital • The 'look and feel' • When it's lacking | 2m 50s | https://youtu.be/LVLbnucmqTE |
| | 09: What influences the experience of compassionate care? <ul style="list-style-type: none"> • Perceptions of stigma • Trust and relationship building • Vulnerability and humanity | 4m 45s | https://youtu.be/JtnP4br10Sk |
| System Policy and resource implications around substance use and end of life care across a range of settings. | 10: Availability and access to appropriate care <ul style="list-style-type: none"> • What's needed? • When and where? • Who can provide it? | 4m 15s | https://youtu.be/6u2PVj_audQ |
| | 11: What's needed to give real choice? <ul style="list-style-type: none"> • Understanding the issues people face • Challenging stigma and shame • Confidence in and coherence of support | 3m 41 | https://youtu.be/vU1kp7HsGik |
| | 12: Training and development themes <ul style="list-style-type: none"> • Understanding the impact of substance use • Connecting with the 'lived experience' • 'Humanising' practice | 3m 56s | https://youtu.be/Qeij8IcracY |

