End-of-life care for people using substances

Sam Wright, SUAB, Dept of Sociology, ManMet
Ellie McNeil, Chief Executive, YMCA Together

COMMUNITY FUND
Manchester Metropolitan University
FUNDED BY NIHR | National Institute for Health Research
YMCA TOGETHER

Our body of work

6 strand exploratory project

- Funder: National Lottery Community Fund, 2016-2018

Good practice guidance

- Funder: NLCF, 2019

https://endoflifecaresubstanceuse.com/wp-content/uploads/2022/02/Good-practice-guidance-EoLC-and-SU-April-2019-Web-version.pdf

Policy Standards: a working document

- Funder: Metropolis, Manchester Met, 2019

https://endoflifecaresubstanceuse.com/wp-content/uploads/2022/02/Policy-Standards-SU-and-EoLC-May-2019.pdf

Development of new model of care

- Participatory action and mixed methods research
- Funder: NIHR, 2019-2022

What have we learnt?

- Many barriers to accessing services - even when their substance use is in the past
- Negative experiences of care and a fear of stigmatising HSCP attitudes
- Isolation, avoidance of services and late presentation to healthcare
- Many services and staff insufficiently equipped to respond
- People’s health and social care needs often not met

What should EoLC look like?

- Clarity of EoL diagnosis
- Timely practical assistance
- Regular emotional support
- Compassion
- Support for informal carers

More commonly it can be like…

- Not knowing how ill you actually are
- Little / no professional input
- Unsupported family / carers
- Feeling lucky to meet health / social care practitioners who do not judge you harshly

Good practice and policy guides:

- Philosophy of care / service
- Joint working
- Talking about it
- Symptom & pain management
- Support for staff
- Family, friends and caregivers

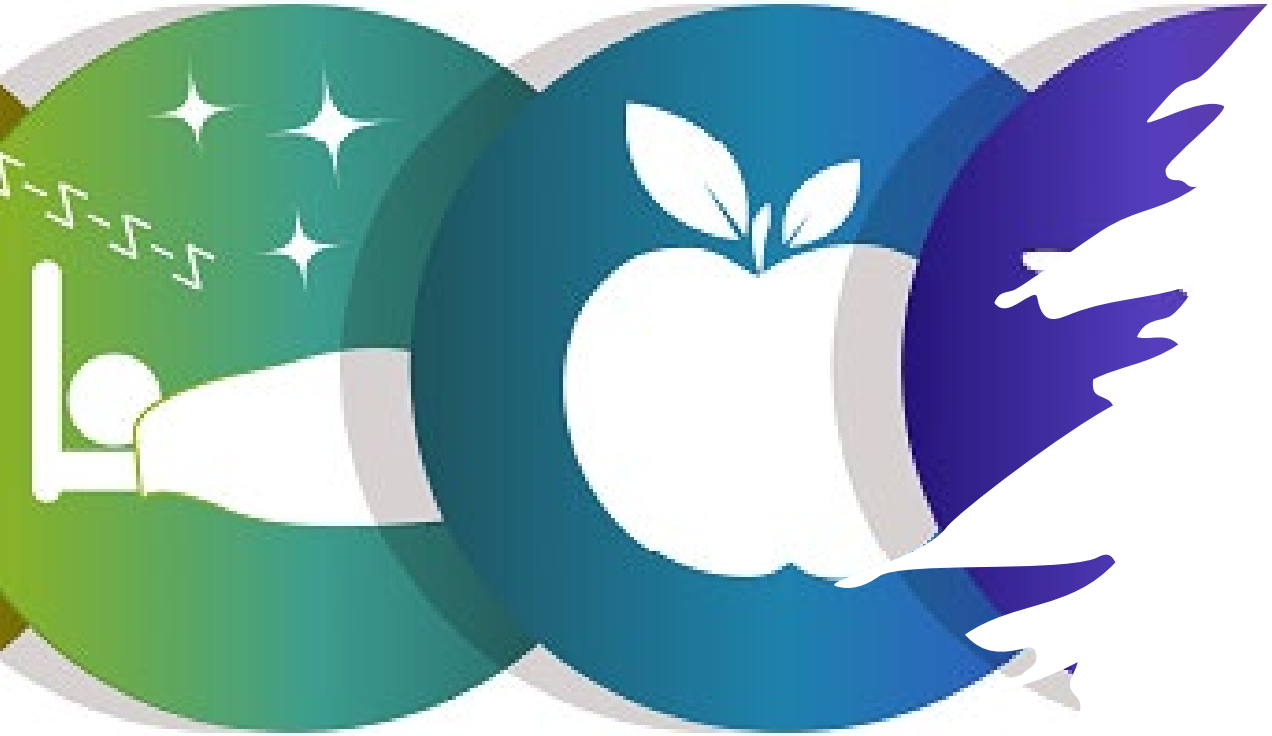
Available at: endoflifecaresubstanceuse.com

Key messages for practice

- Link practitioners across the substance use and P/EoLC fields
- Develop practitioners' knowledge and confidence to enable them to talk about both SU and health problems
- Assess family caregivers' support needs: how their relative's SU affects them and their decision-making responsibilities
- Sufficient support for practitioners undertaking this work.

Support for staff

1. Team/MDT approach to provide care and support decision-making
2. Emotionally responsive teams and managers
3. Regular (internal / external) supervision around loss and bereavement
4. Pairing practitioners for mutual support (or where risks are perceived)
5. Adapting existing guidance on managing multiple, long-term conditions



The reality

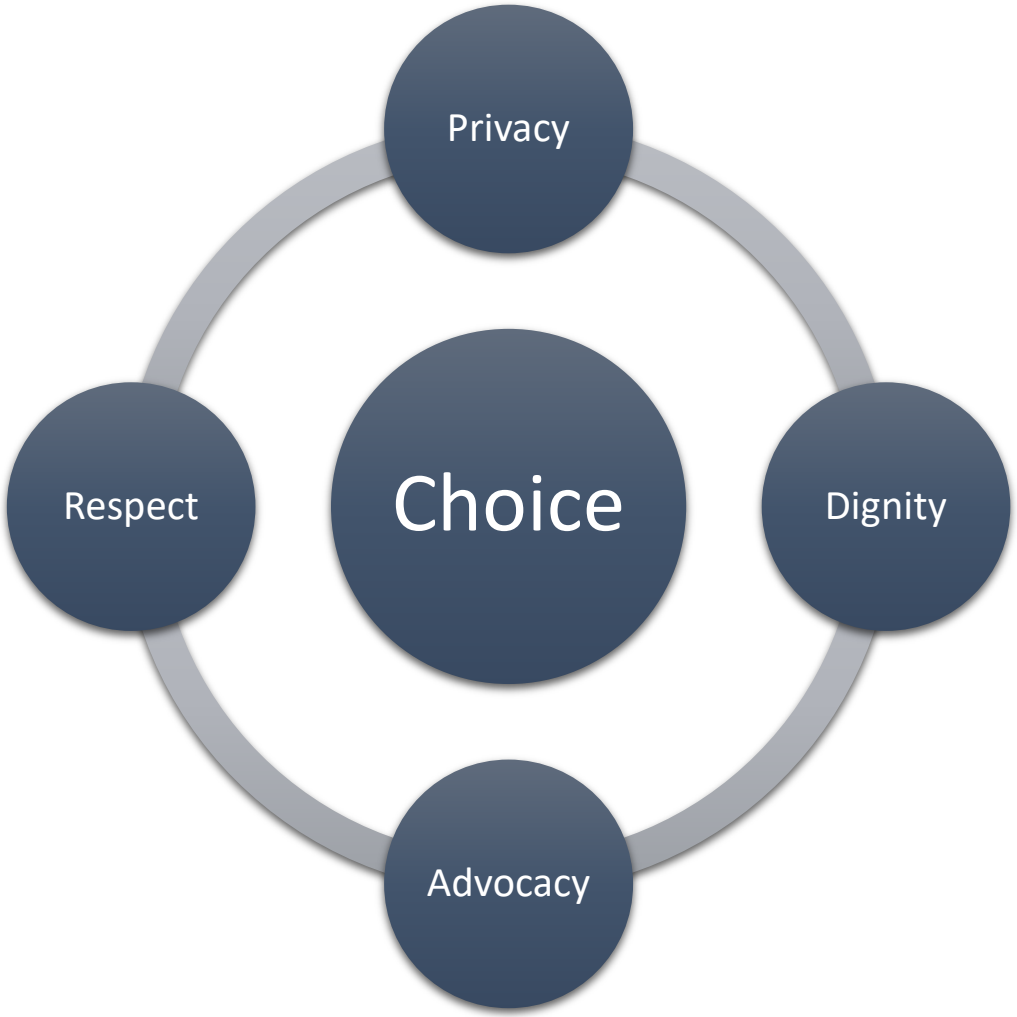
In 2021 there were 45 deaths from people experiencing homelessness in Liverpool

The average age for male deaths was 49.1 years and the average age for female deaths was 40.3 years

Common Physical Health concerns include;

- Chronic Chest & Respiratory Problems
- Wounds Skin Ulcers and other Skin concerns
- Musculoskeletal problems
- In comparison with general population increased drug and alcohol use
- Untreated, undiagnosed health

Our commitment to Quality Care



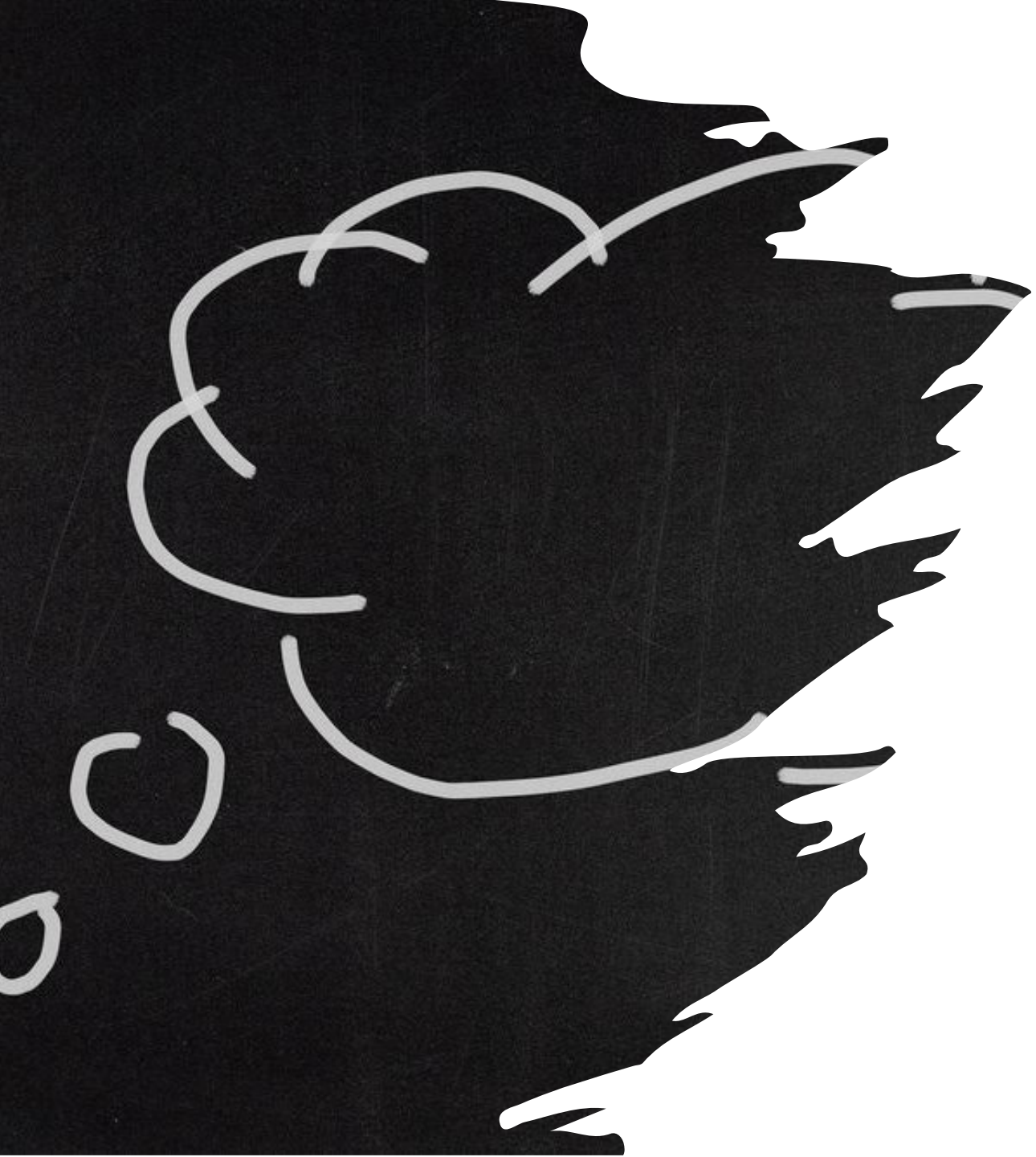
Psychologically informed approach

- Relational working understanding what is sitting underneath the presenting behaviours
- Changing the way we offer services and support access to other services
- Flexible, responsive and without judgement
- Reflective practice

Our Work

Using the resources developed by MMU we have put in place:

- End of Life champions based in all services
- Upskilling, Training, Support & Toolkits
- Continuing to build partnerships to support this work
- Continuing to highlight the barriers to accessing health care for our client group
- Talking about end-of-life care
- A commitment to providing Quality End of Life Care
- After death care - Remembrance and reflection



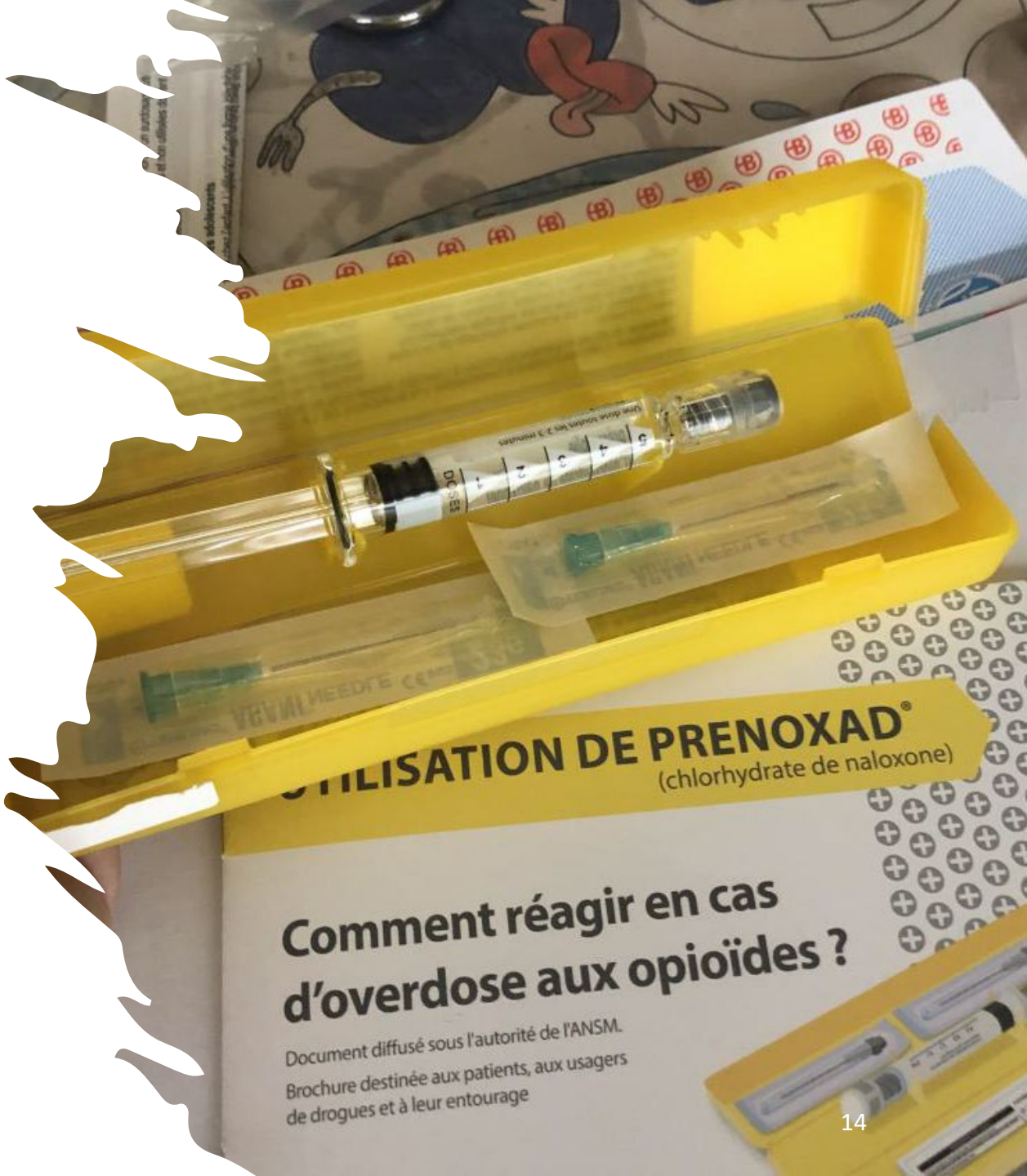
Identifying and supporting

‘Would you be surprised if this person was to die within the next 6-12 months?’

Identifying and supporting

What are the signs someone may be approaching the last 6-12 months of their life

- Non engagement with health services
- Missed appointment
- Repeated hospital admissions
- Repeated overdose and use of naloxone
- Non compliance with medication and treatments
- Visual deterioration in physical appearance
- Self neglect
- Increased drug and alcohol use



Not always a formal diagnosis

- Deteriorating and not diagnosed or accessing support for their health
- Diagnosed and palliative care
- Deteriorating and diagnosed refusing to access support for their health
- Some health concerns and risky behaviours
- Diagnosed and palliative care and now EoL

Knowing someone's wishes

How could we start to log conversations? What are their Beliefs? Priorities? Non negotiables? What needs to be parked and revisited?

Considering these areas……..

Physical

Psychologically

Environmental

Cultural

Spiritual

Social

Case Study

- Creating an environment that considers Privacy,
- Respect and Dignity of the persons needs and situation
- Person Centred Non Judgemental Care
- Considering who is important to that person- Other residents, Family, Pets
- Where desired support independence, choice & control
- Wrap around services- In reach
- Support & Training for staff
- Debrief – Reflection and continuous practice improvement
- Afterlife- Remembrance/ Memorial garden

Care After Death

"Seeing death as the end of life is like seeing the horizon as the end of the ocean"

How people need to be treated:

Information, Identification and Assessment

- Clear, honest, and open communication; ‘No Bullshit’
- Supported to consider and express what they need
- Informed and supported re: the use of advanced directives

Non-judgemental practice

- Find points of connection to build relatability and trust
- Understand and accept who is important in the person’s life
- The need for trust in managing pain medication
- Recognise areas of particular emotional sensitivity
- Recognise the roots of your/colleagues’ defensive practice
- Avoid or question potential myths and stereotypes

Support for staff

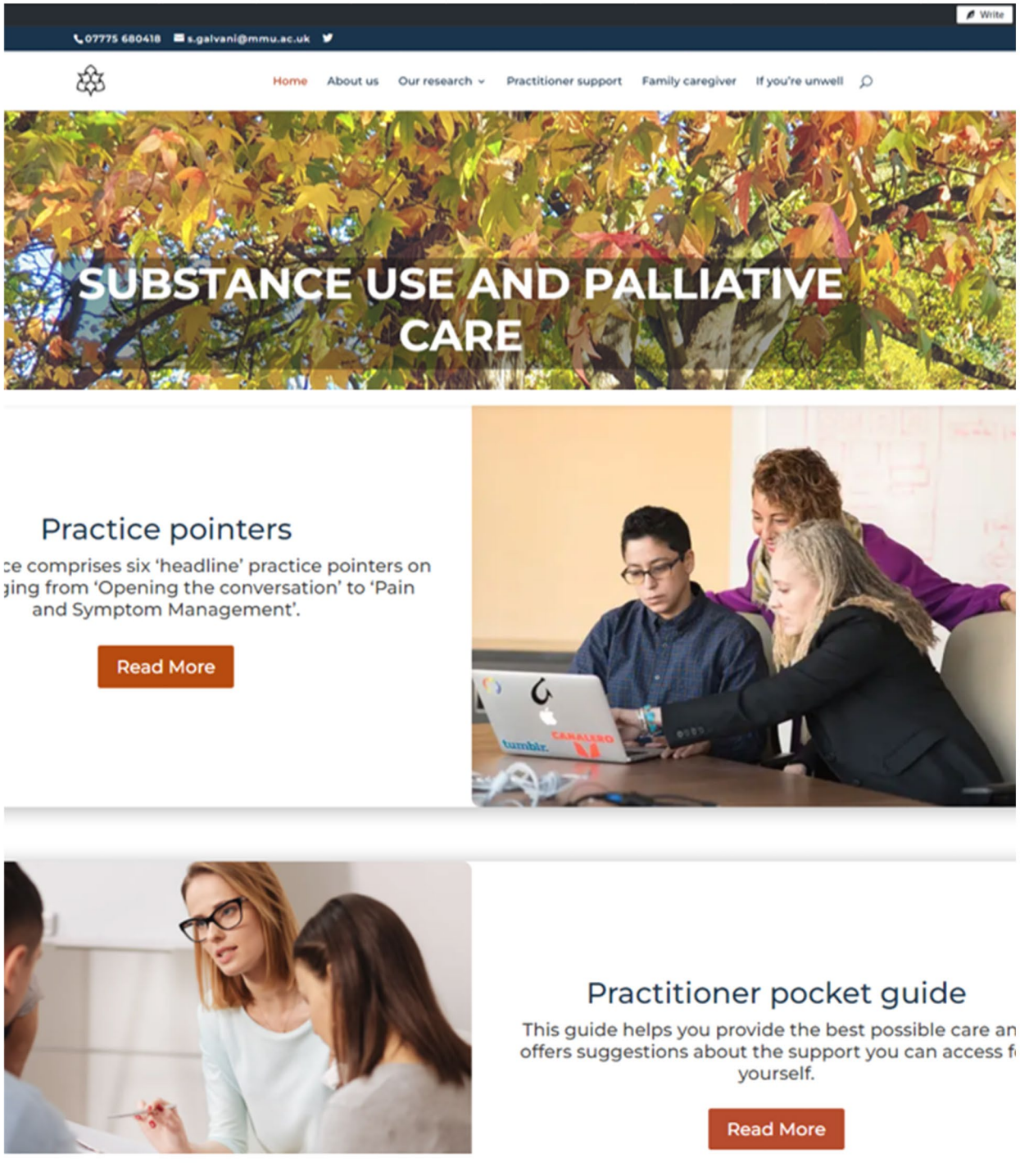
- Look after staff!
- Build greater participation in the range of support services involved

Support for family and friends

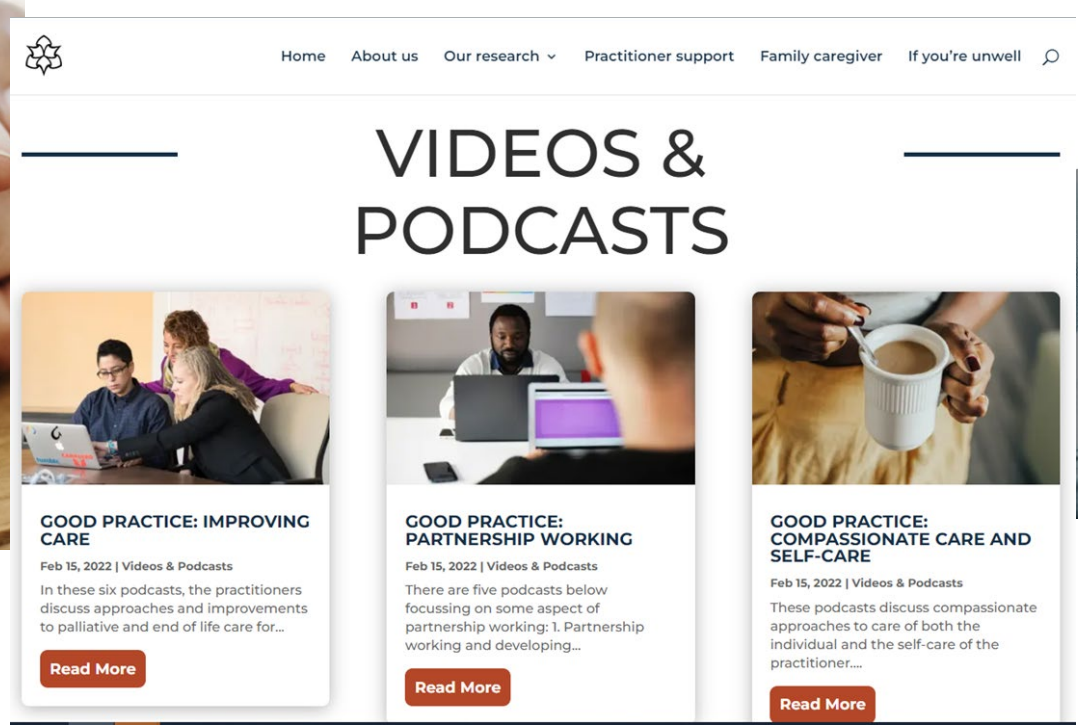
- Enhance support for friends
- Work with individual needs and family dynamics

Developing resources

- Having disseminated the model to all 10 partner agencies, we want to expand training nationally
- Deliver the practitioner and family support forums
- Continue developing and adding resources to the website




What families need to know
ALCOHOL CHANGE UK
Caring for someone with an alcohol or drug problem who is seriously ill
Adfam
Manchester Metropolitan University
Author: Dr Sam Wright, Manchester Metropolitan University


Home
About us
Our research
Practitioner support
Family caregiver
If you're unwell
VIDEOS & PODCASTS
GOOD PRACTICE: IMPROVING CARE
Feb 15, 2022 | Videos & Podcasts
In these six podcasts, the practitioners discuss approaches and improvements to palliative and end of life care for...
Read More
GOOD PRACTICE: PARTNERSHIP WORKING
Feb 15, 2022 | Videos & Podcasts
There are five podcasts below focussing on some aspect of partnership working: 1. Partnership working and developing...
Read More
GOOD PRACTICE: COMPASSIONATE CARE AND SELF-CARE
Feb 15, 2022 | Videos & Podcasts
These podcasts discuss compassionate approaches to care of both the individual and the self-care of the practitioner....
Read More


Manchester Metropolitan University
FUNDED BY NIHR | National Institute for Health Research
VOICEBOX inc.
Caring for someone using alcohol or drugs whose health is poor
Essential Information for Family, Friends and Carers
December 2021

Thank you for listening

Sam Wright

Email: sam.wright@mmu.ac.uk,

Tel: +44 (0)7815 595609

endoflifecaresubstanceuse.com

@SUABManMet

Ellie McNeil

Email: ellie.mcneil@ymcatogether.org.uk

YMCAtogether.org.uk

@EllieYMCA