

# Supporting homeless people with advanced liver disease approaching the end of life

May 2011

In this report we present the findings of research carried out by the Marie Curie Palliative Care Research Unit at University College London. The work was commissioned by St Mungo's and Marie Curie Cancer Care as a result of a joint project funded by the Department of Health to enhance end of life care for people who are homeless.

## Acknowledgements

We would like to thank the staff from St Mungo's, who gave us their time to participate in focus group meetings and also Alan Giddings, the archivist at St Mungo's for his assistance in retrieving documentation. We also thank the project steering group for their advice and input.

## Project team

**Sarah Davis** is a research associate at the Marie Curie Palliative Care Research Unit, UCL.  
[s.davis@medsch.ucl.ac.uk](mailto:s.davis@medsch.ucl.ac.uk)

**Peter Kennedy** is the Palliative Care Coordinator at St Mungo's. [peter.kennedy@mungos.org.uk](mailto:peter.kennedy@mungos.org.uk)

**Wendy Greenish** is a project manager based at Marie Curie Cancer Care's offices in Vauxhall, London.  
[wendy.greenish@mariecurie.org.uk](mailto:wendy.greenish@mariecurie.org.uk)

**Dr Louise Jones** is Head of the Marie Curie Palliative Care Research Unit, UCL and Palliative Care Research Adviser to Marie Curie Cancer Care. [l.jones@medsch.ucl.ac.uk](mailto:l.jones@medsch.ucl.ac.uk)

## Foreword

It is our belief that societies should be judged by the compassion they show to all their members, whatever their circumstances.

Over the past three years, Marie Curie Cancer Care and St Mungo's have been working together, supported by funding from the Department of Health, to improve end of life care for people who are homeless.

Of the thousands of people that St Mungo's supports each year, around 50 will die in their care, with advanced liver failure being the most common cause. Their last weeks of life are frequently distressing and their painful physical and psychological symptoms are often accompanied by a reluctance to be admitted to hospital, and an inability to feel comfortable once there. And as staff, friends and family may not be aware that the person is in the final stages of life, their death often comes as a shock.

This report is powerful testimony to the experiences of people with advanced liver disease who die whilst living in hostel care. It is not easy or comfortable reading, but we make no apology for sharing the stark reality and asking what can be done.

Through examining case histories and speaking with staff at St Mungo's, the research team at the Marie Curie Palliative Care Unit at University College London, has built up a picture of the physical and behavioural changes that indicate when a person with liver failure is nearing the end of life.

By discovering what the key signs of deterioration are, we can work to ensure they receive the right palliative care at the right time, whether it be appropriate pain relief, psycho-social support or discussing future needs and wishes. And by understanding the journey the person is on, we can better prepare their friends and relatives.

As part of this project, we introduced and hope to maintain a Palliative Care Co-ordinator at St Mungo's to support staff and residents. Part of this role has involved the development of training materials and an end of life care resource pack for professionals working with terminally ill homeless people.

Although our funding is now coming to an end, we would like to see more frontline staff such as Hostel Key Workers or Substance Misuse Workers trained to recognise when people are reaching the end of life so that the right care and bereavement support can be provided. But there is still more to do. Our research has highlighted the need for intermediate care services and we would like to investigate the cost of establishing the service configurations that would better meet the needs of homeless people but which could also benefit all those who are hard to reach via existing services.

By partnering with other charities who support the homeless we could undertake such research, and we encourage them to join us as we work to ensure that all homeless people who are terminally ill experience the best possible care at the end of their lives: care that respects their wishes and is available in a place of their choosing.



Charles Fraser  
Chief Executive  
St Mungo's



Thomas Hughes-Hallett  
Chief Executive  
Marie Curie Cancer Care

## Executive summary

Since 2008, the two charities St Mungo's and Marie Curie Cancer Care have been working in partnership to explore ways to improve care for homeless people around the time that they are dying. This initiative received funding for a three year period from the Department of Health. The main component has been a new and groundbreaking post of Palliative Care Co-ordinator at St Mungo's which has enabled an expert to work with residents and staff. Through this work, we began to understand more clearly the range of problems that arise in caring for homeless people as their condition deteriorates and the difficulties for professionals involved in their day to day welfare.

St Mungo's accommodates approximately 1,600 residents each night, aged from 18 years upwards. Over the course of a year the charity supports around 3,000 residents with accommodation but more than 10,000 with housing, health and employment services. On average 50 people who are receiving care from St Mungo's die each year.

We learned from the Palliative Care Co-ordinator that many of those who are dying have advanced liver failure. When residents are facing death, although it may be clear that they are unwell, often neither residents nor professionals seem well prepared for the events that follow. Indicators of likely prognosis and signs of deteriorating health that might alert staff that a resident may be approaching death are poorly understood and thus opportunities for possible interventions to provide support at the end of life are not being recognised. Many deaths that have occurred were not anticipated and thus have appeared shocking to fellow residents and some staff.

So that we might suggest ways in which to improve the experiences of both residents and staff, a more in-depth understanding of the weeks and months preceding the deaths of residents was needed. In particular we need to understand any key changes in the physical condition or behaviour of residents that might indicate significant deterioration and the increased likelihood of death. Recognising these 'tipping points' might enable staff to intervene in a timely fashion for example offering further psycho-social support and active palliative care.

In this report we present the findings of a detailed review of the case notes held by St Mungo's for people affected by advanced liver failure who died between January 2009 and April 2010. We also conducted focus group discussions with staff from St Mungo's to explore their experiences of the deaths of residents. This research was conducted by the Marie Curie Palliative Care Research Unit at University College London. We aimed to identify changes in the general condition or behaviour of homeless people with advanced liver disease that might indicate their health was deteriorating and they could soon be facing death.

## Our results:

The majority of the deaths of people receiving care from St Mungo's each year are associated with liver failure (31 out of 56 deaths in 2009/10). In this group there is a high rate of hospital admissions, as well as significant morbidity and distress in the last six months of life.

The care of homeless people with liver failure is hampered by their complex needs, usually a combination of physical, psychological and social problems that may co-exist with substance abuse. Care must be considered within the context that many homeless people have survived difficult backgrounds, served in the armed forces or been in prison and find usual relationships challenging. Liver failure runs an unpredictable course and it is often difficult to judge when significant deterioration is occurring and the end of life is approaching. When hostel staff try to work with residents to address their problems, residents are often reluctant to reduce their drinking, have limited insight into their condition and frequently are unwilling to take up services offering treatment. Any attempts to encourage homeless people to seek help must be tempered by respect for their personal autonomy and rights of individual choice.

Currently, neither staff, healthcare professionals nor residents find it easy to link the signs and behaviours of advanced liver disease with possibilities for palliative care interventions such as exploring their choices, future needs and wishes, or agreeing a suitable plan for future care. Residents often do not receive appropriate pain relief which may encourage self medication with alcohol and/or drugs. As a result of all these factors, most deaths occur suddenly, either in hostels or hospital, and are perceived to be unexpected and are therefore not anticipated. Such events may be challenging for those close to the deceased such as fellow residents, staff and family members.

Hostel key workers or substance misuse workers are best placed to recognise when a resident's condition is deteriorating. In retrospect, it is often possible to identify key signs that could have alerted staff to the likelihood that death was approaching. Most commonly, around two weeks before death, some changes in physical condition or behaviour were noted such as increase in jaundice, spontaneous bleeding, low mood, social isolation or a reduction in self care.

By enhancing the capacity of staff to be alert to key changes in health or behaviour we may optimise their ability to anticipate deterioration and death. This may provide opportunities for professionals to intervene to enhance the well-being of residents. For example professionals might consider attempting to offer additional psychological support, to facilitate meetings with hostel staff, significant family members or friends, to discuss with residents their preferences for care or to explore the possibilities for seeking medical interventions. In addition,

as there is greater anticipation of likely deaths, there may be some benefits for staff in improving their own experiences of bereavement and those of fellow residents.

To help them to respond effectively, hostel staff would benefit from training to improve their knowledge of and communication skills in palliative care issues. This would maximise their capacity to support residents and improve their confidence in care towards the end of life and around the time of death. A resource pack might be developed that includes a fact sheet of the signs and symptoms of liver disease and local information on services and end of life care resources available within the locality. A system of bereavement support (maybe in co-operation with other bereavement agencies) and debriefing on the circumstances surrounding deaths when they occur would help staff both to deal with their own feelings and to fulfil their role of offering support to grieving residents and bereaved relatives. Some of these services are currently being developed within St Mungo's by the Palliative Care Co-ordinator. There may be opportunities for sharing this knowledge with other organisations providing support to homeless people as their health deteriorates.

### **In summary:**

- A combination of physical, psychological and behavioural signs and symptoms are observed in homeless people with liver disease as their health deteriorates and the end of life approaches.
- Memory problems are common among residents and caused them some distress.
- Residents are often in denial about their alcohol intake and its impact on their health. They can be reluctant to take responsibility for their drinking or to work with health or social care services.
- The majority of residents are registered with a GP but do not use their services.
- Residents access healthcare mostly from secondary services in the last six months of life. However, this is limited by their reluctance to be admitted to hospital because of restrictions placed on their behaviour.
- The severity of illness is rarely appreciated as there is a lack of communication between secondary care and hostel staff. Efforts to improve this must be considered in the context of preserving autonomy for the homeless person whilst aiming to optimise their care.
- Hostel staff are not often able to plan for end of life care with residents and access to palliative care is minimal.
- Deaths of residents are not often anticipated and frequently appear to occur suddenly.
- Key signs of deterioration include increased jaundice, spontaneous bleeding, low mood, social isolation and poor self care.
- Hostel staff and other residents need support following the death of a resident.

This work complements the approach of the London Pathway project [www.londonpathway.org.uk](http://www.londonpathway.org.uk) being developed across north London. Although not specific to end of life care, the London Pathway aims to encourage secondary care to work with hostels and other community support organisations for homeless people. Advice specific for end of life care for the homeless is now available in the Route to Success series published by the National End of Life Care Programme in England [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

# Recommendations

We anticipate that the following recommendations could be realised rapidly:

- **Training for staff working with homeless people to provide support as health deteriorates and death approaches.** Hostel staff, such as key workers and substance misuse workers, who are in regular contact with their clients, are most likely to recognise when the physical condition and behaviour of a homeless person are deteriorating and the end of life may be approaching. Training would include learning to recognise the key physical and behavioural signs of change that may offer opportunities for interventions. Supplementary training in palliative care issues and communication skills could help staff feel more confident about talking to residents and supporting them as they reach this phase. Materials are currently being developed by the Palliative Care Co-ordinator and complement other initiatives such as the Department of Health *Routes to Success* document.
- **An end of life care resource pack for staff working with homeless people.** This would be aimed at increasing knowledge of health and social care needs of people in the last few months of life. It could include a fact sheet on signs and symptoms of liver disease and other life-limiting illnesses as well as general information on local end of life services that, with permission, staff could access for residents.
- **Access to bereavement support that acknowledges the challenges faced by staff and other residents in coming to terms with unanticipated deaths.** Staff and residents in hostels would benefit from extra support following the death of a resident. A system of debriefing discussions may be beneficial. Educational sessions on loss, bereavement and grief would enhance the ability of staff to support other homeless people who are affected by a death, as well as family and friends of the deceased. Staff may also feel empowered to raise in a more timely fashion issues of end of life care with homeless people whose health is deteriorating.
- **Maintenance of the role of the Palliative Care Co-ordinator** and its extension to other sites to support the implementation of these recommendations.

In the longer term we would like to plan the following further research:

- In depth qualitative work directly with homeless people to explore their needs and current experiences of health and social care as their health deteriorates
- The development and testing of new service configurations to improve these experiences
- An in-depth understanding of the economic costs and benefits of new approaches including the effects of reducing hospital admissions and enabling death in usual place of residence
- Work on innovative solutions that might include a half-way house facility that provides holistic care to homeless people with a range of chronic and life-limiting conditions and could complement other ways of bridging the gap between primary and secondary care.

## Introduction

Funded by a grant from the UK Department of Health 2008–2011, St Mungo's, a London-based charity supporting people who are homeless, has been working in partnership with the national end of life care charity Marie Curie Cancer Care to explore how care could be improved for residents who are dying. A Palliative Care Co-ordinator has been working with staff and residents to increase our understanding of the needs of homeless people as their health deteriorates towards death and how professionals in hostels might be enabled to provide appropriate support. This work identified that a number of residents with alcohol related liver disease experienced deaths that appeared to occur suddenly and had not been anticipated by those involved in their care. Indicators of likely prognosis and signs of deteriorating health that might alert staff that a resident may be approaching the end of life were poorly understood and thus opportunities for possible interventions to provide support at the end of life were not being recognised.

In 2010, the project team and expert steering group invited researchers from Marie Curie's Palliative Care Research Unit at University College London to discuss possibilities for research to enhance our knowledge of care for homeless people who face death. The group decided to conduct a detailed review of the case notes held by St Mungo's of residents supported by the charity who had died from alcohol related liver disease. The notes did not contain specific medical information, but we aimed to identify any documented changes in clinical condition or in behaviour that were noticed by staff during the last year of a resident's life. We used these data to describe the most frequent pathway of care experienced by homeless people with liver failure. To supplement the case review, the research team facilitated focus group discussion with staff from St Mungo's who had worked closely with residents who have died from advanced liver disease, to explore their experiences of supporting residents nearing the end of life.

People who are homeless often present with a combination of physical, psychological and social problems in conjunction with alcohol and drug abuse as well as a background of complex trauma (O'Connell 2005, Department of Health 2010). In this review we report on some aspects of the effects of these complexities. However, we have not attempted to take account of the full effects of these complexities in a systematic way in our interpretation of the findings. Whilst some apparent prognostic features observed were specific to the effects of chronic alcohol abuse, many of the findings, in particular behavioural changes, may be seen as the end of life approaches from a variety of causes.

## Aims of the study

This was an exploratory study to identify the observed changes in physical condition or behaviour of homeless people with liver disease who may be in deteriorating health and approaching the end of life, to inform our understanding of opportunities for interventions such as increased psycho-social or active palliative care, and the development of further research.

## Methods

**CASE NOTE AUDIT:** To identify eligible residents, data collated by St Mungo's on residents' deaths between January 2009 and April 2010 were examined by the research associate and Palliative Care Co-ordinator. Case notes were included in the study once consensus was reached as to their eligibility by looking for evidence of liver disease, liver failure or cirrhosis, hepatitis B or C, multiple organ failure, alcoholic cardiomyopathy (damage to the muscle of the heart), alcohol abuse or heavy drinking, severe symptoms on withdrawal of alcohol, Korsakoff's psychosis, poor memory (that may or may not be related to alcohol abuse).

A total of 56 residents died during this period. We identified that the deaths of 31 residents were eligible for study. The case notes of 27 residents were obtained and reviewed. Two sets of case notes were unobtainable and two were incomplete and so were not included.

Notes were reviewed for the 12 months prior to death. Data were extracted from documented sessions and assessments with key workers, substance misuse workers, mental health workers, regular updates from staff on the resident's day-to-day activities and conduct, verbal or written behaviour warnings, assessments for re-housing and alcohol and drug support referrals recorded in the notes.

Data were collected on documentation of:

1. Physical, psychological and behavioural symptoms
2. Clinical diagnosis and prognosis
3. Health service use in primary and secondary care
4. Health and social care services accessed within St Mungo's and other agencies
5. Circumstances surrounding each death

**Data analysis:** The case notes were read in detail by one member of the research team. Extracted data were entered into a standard proforma (appendix 1) and cases were compared for similarities using categories identified on advice from an expert steering group composed of palliative care specialists in health and social care, and professionals specialist in the care of people who are homeless including experts in substance misuse and community psychiatry. Quotes from staff and residents were also extracted if relevant to the emerging themes.



Supplementary information was obtained from two residents' key workers through a face-to-face interview and a telephone interview.

**FOCUS GROUPS:** Three focus group meetings were held with St Mungo's staff members to provide their perspective on the experiences of residents with advanced liver disease. Structured questions were used in the focus groups to elicit information on the same topics as those in the case note review.

**Selection of participants:** Staff at St Mungo's were invited by poster advertisement to volunteer to take part in the focus group meetings. A total of 16 members of staff came forward and 13 were able to participate. Three focus groups were held at St Mungo's administrative offices; each was composed of between three and six members and was facilitated by one member of the research team whilst another took detailed field notes. Participants worked in a number of different types of accommodation including: a residential care home, semi-independent housing, a hostel for residents with complex needs and general residential hostels. Participants included: key workers, substance use workers, health care coordinators, complex needs workers, intermediate care nurses and deputy hostel managers.

**Data analysis:** Field notes and reflections from each focus group were written up immediately and independently by two researchers. One researcher used field notes taken during the focus group to do this, whilst the other researcher, who facilitated the focus groups, summarised the main information from memory. The researchers then read and re-read both versions of the focus groups and compared them for accuracy.

The data were analysed for thematic content using methodology developed by Ritchie and Lewis (2003). The main themes were drawn out and further sub-themes identified by making comparisons between and within cases. This helped to build up a framework of evidence from the data extracted in the focus groups to supplement the case review findings.

**CONTEXT:** One researcher attended three different types of meetings within the St Mungo's operational structure:

1. The intermediate care nurses at one hostel met to discuss how information about residents with end stage liver disease was recorded in the notes and what their specific needs might be.
2. A discussion forum was run by staff at St Mungo's to consult with residents with alcohol use problems from a number of different hostels about their thoughts on detoxification and rehabilitation treatments.

3. Peter Kennedy, the Palliative Care Co-ordinator at St Mungo's and staff at a hostel met to discuss the strategies needed to support a number of residents with end stage liver disease and the need to provide support for staff.

#### **PROJECT MANAGEMENT AND OVERSIGHT:**

The expert steering group met on five occasions during the course of the study and provided advice on the following:

- The study methodology
- Focus group topic guide
- Interpretation of the findings
- Recommendations

## **Results**

We report the combined findings of the case note review and focus group meetings according to the main themes identified:

### **Symptoms**

- Alcohol and drug abuse
- Diagnosis and prognosis
- Access to services in the community and within St Mungo's
- Use of secondary care
- End of life care and death
- Implications for staff
- Impact on other residents



## Characteristics of the homeless people reviewed in this study

The case notes of 27 St Mungo's residents who had died between January 2009 and April 2010 were reviewed:

- 26 were male and one female.
- Ages ranged from 32 to 84 years with an average age of 55 years (median age range 56).

Age range	No of residents
30-40	4
41-50	5
51-60	9
61-70	7
71-80	0
81-90	2

- 19 residents were white British, four were Irish, one Portuguese, one Afro Caribbean, one Black African and one Black other.
- 19 residents were ex-offenders.
- 16 residents had children.
- 15 residents were documented as having some contact with a family member and 12 residents had no contact.
- 19 residents were documented as having depression, four residents schizophrenia and three a personality disorder.
- 27 residents had a problem with alcohol abuse and 15 were using drugs as well, so were poly substance abusers.
- 26 residents were housed in St Mungo's accommodation across London and one in Oxford.
- 11 residents were housed in first stage hostel accommodation, two in a registered care home, one in a hostel for people with mental health problems, seven residents in hostel accommodation specifically for people with complex needs, and six were housed in semi-independent accommodation.

- Causes of death were documented as the following:
  - 7 drug and alcohol overdoses
  - 5 liver cirrhosis or liver failure
  - 4 ischaemic heart disease
  - 2 pneumonia
  - 2 heart failure
  - 2 alcoholic damage to the muscle of the heart (cardiomyopathy)
  - 1 pulmonary TB
  - 1 kidney failure
  - 1 respiratory failure
  - 1 head injury
  - 1 natural causes

# Symptoms prevalent in last six months of life

## Key messages

- Evidence that physical symptoms worsen as death approaches
- Evidence of particular physical symptoms that are unique to alcohol abuse
- Memory problems were prevalent amongst residents and caused them distress
- Evidence of psychological symptoms increasing
- Evidence of behaviour changes
- Residents requested urgent access to detoxification but were often unable to commit to rehabilitation. Hostel staff were able easily to list the symptoms of liver failure

## Supporting evidence

The following symptoms were identified in the terminal phase by staff in the focus groups. Documented evidence from the case review is included alongside each identified symptom:

## Physical symptoms

1. Distended abdomen - three residents had abdominal distension due to the collection of fluid (ascities)
2. Jaundice - yellow discolouration of the skin and eyes documented as present in four residents
3. Bleeding - eight residents had problems with bleeding; four from the rectum, two from the mouth and two from the nose
4. Not eating - nine residents had evidence of a loss of interest in food and lack of appetite
5. Memory loss - seven had poor memory and two had alcohol related dementia (Korsakoff's psychosis)
6. Fluid in the legs, difficulties with walking and balance - six residents
7. Prominent veins
8. Tiredness, malaise
9. Confusion - this was noted for four residents from the last eight weeks of life
10. Withdrawal symptoms - six residents had withdrawal fits; shakes, vomiting and hallucinations were common

Evidence from the case note review found that residents presented with a number of the above symptoms at any one time.

- Pain was a frequent symptom with eight residents complaining of pain in the abdomen and stomach and less frequently in the legs and chest.

---

### Case review + personal communication with key worker:

One resident had a very distended abdomen that he kept trying to cover up with clothing as it caused him embarrassment. He had had previous hospital admissions for drainage of ascites. His complexion appeared dark yellow and he complained of feeling weak and unwell. With bleeding from the rectum. He would stagger to the shops to buy alcohol and then lock himself away in his room. Staff had to regularly encourage him to eat. His memory was very poor. He became intoxicated very easily on only a couple of cans of alcohol. The pain in his abdomen became so severe that he asked to be admitted to hospital for treatment. He remained there for five weeks until he died.

- 
- Seven residents were documented as feeling unwell and four of looking unwell in the last few months of life.
  - Weakness, frailty and falls were common, but often unexplained.
  - Other symptoms included rashes on torso, spontaneous bruising, weight loss, swollen testes and fluid leakage from legs.

## Focus group comments

*“Jaundice is the main symptom everyone looks for. Bleeding from a ruptured ulcer or varices is common.”*

*“Lot of double incontinence - complete lack of control.”*

*“One went off the rails - two were unwilling to engage and stayed in their rooms.”*

*“Tend to drink more towards the end - resigned to their fate.”*

*“Of course some residents are just determined to go out with a bang and drink as much as they can.”*

*“They will be spitting blood and say - it's just my stomach lining - to prevent people becoming alarmed by it.”*

*“When residents start to spit blood that is when you know there is a problem.”*

*“I will have meetings with clients but I know that they will not remember a week later.”*

*“Some have cognitive problems for a long time; some can go quickly.”*

*“Memory is definitely an issue.”*

*“As they become more ill, they stay at home more and rely on friends to access alcohol for them.”*

## Psychological symptoms:

- Eight residents were documented as having low mood from three months prior to death
- Panic and anxiety was also noted in a few residents up to two weeks before death

## Behavioural symptoms:

- Bingeing on alcohol (in conjunction with drugs in seven cases) was seen in 12 residents usually between 1 – 4 weeks before they died. In some cases it was very frequent.

---

**Case review:** One resident who was unable to address his alcohol and drug intake went on a binge in the last month of life and was under some physical distress because it was documented – “He looks a ghost of his former self ....he seems to be suffering from physical health problems and has lost so much weight”. The resident died five days later from a drug and alcohol overdose.

---

- Four residents in the last two months of life requested some form of social contact with family members even if they were estranged. One resident was keen to address unresolved problems from childhood and one resident changed his name by deed poll two months before his death.

---

**Case review:** One resident was intent on visiting his mother's grave in Ireland two months before he died.

---

**Case review:** One resident travelled abroad to see relatives in a very poor state of health five weeks before he died and managed to return to the hostel a week before his death.

---

- Social isolation became more common as residents' condition deteriorated. Hiding themselves away in their rooms (four) from staff and residents was not uncommon, particularly when residents felt unwell.
- Requests and demands for detoxification occurred in seven residents in the last six months of life which may have related to an increase in physical symptoms.
- Seven residents received behaviour warnings from staff either verbally or in writing in the last two months of life. For some this related to excessive bingeing that often resulted in problems with visitors and loud noise. Other reasons for behaviour warnings included very aggressive behaviour that may have occurred because residents were under some form of physical distress.
- For five residents as their physical condition deteriorated they became unkempt and unwilling to wash or pay attention to their personal hygiene.

---

**Focus group comment:** “Some residents are doubly incontinent but tend to sit or lie in the mess as they do not want to be disturbed.”

---

## Focus group comments

*“One resident was very anxious – talking about death all the time and going over and over what had happened to him in his lifetime and where he went wrong.”*

*“Stomachs are extended but they are not eating or mobilising.”*

*“They shut themselves away in isolation but still continue to drink.”*

*“They are unable to get out of bed either because of being too inebriated and because they feel too unwell.”*

*“Some residents cannot eat – they want cold stuff, their appetite changes; they have to be prompted to eat.”*

*“Balance is affected as legs become weak.”*

*“They do flag if there is blood in their stools or vomit.”*

*“Very tired as well as jaundiced.”*

*“Tend to see people sleeping more and see them around less.”*

*“Can be dis-inhibited and confused.”*

*“People become more irritable and agitated as their condition worsens.”*

*“Low mood and depression are quite common.”*

# Alcohol and drug abuse

## Key messages

- Many homeless people were in denial about their alcohol problem and unable to take responsibility for their drinking
- Bingeing on alcohol /and drugs in almost 50% of residents prior to death
- Alcohol and drug overdoses common
- Hepatitis C frequent amongst residents
- Poor memory was a common problem
- Limited insight about their condition
- Detoxification (detox) was sometimes requested in the last six months of life
- The majority of residents were depressed
- Residents reluctant to engage with services
- Boredom may have influenced alcohol intake
- Alcohol use was often a reason for family/relationship breakdown

## Supporting evidence

- 27 residents had a problem with alcohol abuse (often from 15-16 years of age) and 15 were also using drugs. Some were documented as using drugs to reduce their alcohol intake and others were using alcohol to reduce their drug intake and in some cases to provide pain relief.
- Seven deaths were attributed to alcohol and drug overdose.
- 11 residents were diagnosed with Hepatitis C.
- Alcohol and drug use blamed for relationship/ family breakdown documented in four cases.
- 12 residents were in denial about the amount of alcohol they were drinking.
- There was a reluctance seen in at least nine residents to take responsibility for their drinking.

---

**Case review:** One resident, three weeks prior to his death, went on a binge, drinking very heavily. He was drinking spirits: whisky and brandy instead of his usual lager. When staff talked to him about the need to reduce his alcohol consumption he said: "life is not worth living without alcohol." He failed to eat; he had two withdrawal fits and became weak and unwell but preferred not to work with any medical services. He continued to drink but became confused, disorientated and dehydrated and retreated into the hostel. He developed alcohol withdrawal symptoms but still refused any medical interventions. He died a week later in the hostel.

---

- Bingeing on alcohol (seven residents in conjunction with drugs) was seen in 12 residents usually between 1 – 4 weeks before they died; in some cases it was constant.

---

**Focus group comment:** "Many residents are aware of the dangers of drinking but are past caring as they are intent on drinking as much as possible. A new phenomenon has been the introduction of drugs into some residents' lives that you wouldn't expect, as they never had a history of drug taking before. This is all part of their desire to obliterate any feelings with anything they can use. It also occurs when alcohol doesn't have the desired effect anymore."

---

- Seven residents had memory problems that were attributed by staff to their chronic alcohol use over a period of time. They were unable to remember appointments, information they were told, or arrangements.

---

**Case review:** One resident's memory was so badly affected that if he went outside the hostel he had to have a sign pinned to him giving him his name, the address of the hostel in which he lived and directions about how to get there to help him if he got lost.

---

## Focus group comments

*"The majority of residents are in denial about their drinking and continue to do it as they can't see a way out of it – it has become part of their lives."*

*"Drinking is a habit as they have so much free time and no structure."*

*"If a resident is seen early in the day and is drunk, this is an indicator that his liver is no longer so tolerant; they become intoxicated more quickly when taking alcohol. Can talk to them in the morning but one or two cans and all over the place."*

*"A lot of residents fear that if they stop drinking they will lose their benefits."*

*"Binge drinking is common, the same type of alcohol they were drinking before but in larger doses."*

*"Some residents do show an interest in detox but not with a deep intention of seeing it through. They only want it to help them feel better physically and then they want to be able to come back to the hostel where they will be able to drink again."*

*"Staff keep alcohol on standby to give to residents suffering from withdrawal fits."*

- A few residents suffered from blackouts where they had no memory of what had happened to them when they regained consciousness.
- Two residents were diagnosed with alcohol related dementia (Korsakoff's psychosis). Staff had to regularly repeat information, accompany residents to appointments to make sure they remembered to attend, assist them to get there and listen to the medical information so that they could repeat it to them later.
- Requests and demands for detox occurred in seven residents in the last six months of life which may have been related to an increase in their physical symptoms.
- Depression was common with 19/27 of residents having a diagnosis of depression documented in their notes but only 6/27 were receiving anti depressant medication. In some cases it was reported that due to their high alcohol intake doctors were unwilling to prescribe anti depressant medication.

---

**Focus group comment:** "Binge drinking is a common reaction to realising how ill you are. One of our residents following diagnosis started fighting with everyone, then he went on a massive binge and this eventually culminated in him demanding to go into detox."

---

- Four residents in the last few months of life hid themselves away in their rooms socially isolating themselves as their condition started to deteriorate.

---

**Focus group comment:** One staff member referred to the fact that the reason some residents shut themselves because of a sense of guilt about their continued drinking and they do not want others to comment or witness them doing it.

---

- 15 residents were documented as not engaging with alcohol services and five of them did not perceive themselves to have a problem with alcohol.
- Focus group comment: One client was bleeding from the mouth but refused to go in the ambulance to hospital and continued drinking.
- Six residents had alcohol withdrawal symptoms such as fits, nausea, vomiting and shakes and three residents had hallucinations.

---

**Case review:** One resident had to have two cans of alcoholic drink first thing in the morning before the shakes and vomiting would stop.

---

**Case review:** One resident had a history of chronic alcoholism and blackouts. He was alarmed that his behaviour changed as a result of his drinking: "I do the queerest things when I'm drunk." The resident was upset after he had punched a friend the night before. He gave up drinking for a time but returned to it as he explained "as a result of boredom" and was dead six months later due to alcohol ingestion.

---

## Focus group comments

*"People are scared to go into rehab – such a life change – scared to look at the reason for their drinking."*

*"First thing in the morning, the physical symptoms are worse, shaking, dry vomiting, alcohol induced fits, sweating."*

*"Environmental factors play a part – they are bored, there is no real structure, they have nothing to do."*

*"One client remained sober for seven weeks after being in hospital (very reflective during that time) but returned to drinking."*

*"It's very complex, there are a lot of feelings of regret and blame."*

*"Some residents are on a self destruct course – nothing is going to stop them, as they are so intent on drinking as much as possible."*



# Diagnosis and prognosis

## Key messages

- Limited evidence of a recorded diagnosis of end stage liver disease, however a lot of evidence recorded of problems with the residents' livers
- Complex physical, psychological and social problems in conjunction with substance abuse contributed to difficulties in making a diagnosis and estimating prognosis
- No detailed information of how much the staff and resident were aware of the diagnosis and prognosis
- Many residents chose to ignore the advice given to them by health professionals about their drinking habits
- Memory problems contributed to residents not retaining information about their diagnosis
- Hostel staff witnessed people who displayed all the signs of end stage liver failure for variable periods of time, challenging their ability to predict when a resident is reaching the end of life

## Supporting evidence

- The case note review found that 18/27 residents had one or more liver problems associated with alcohol abuse listed such as increased iron deposits, abscesses and abdominal venous thrombosis.
- Hepatitis C was the most common problem - 11/27 residents. Six residents had alcoholic liver disease, cirrhosis of the liver or liver failure listed as a diagnosis and four were listed as having liver problems.
- 9/27 residents were not documented as having liver problems but in all 27 of the case notes reviewed there was evidence of alcohol abuse and in 15 of them additional evidence of drug misuse. (NB Social care notes may not necessarily document medical problems.)

---

**Case review:** One resident following repeated warnings of deteriorating health claimed: "I'm not yellow yet! .....I was given months to live years ago.....I'm not interested in anyone telling me what to do! "

---

- 13/27 residents were warned by health professionals of the severe risks to their health if they did not stop drinking.
- 

**Focus group comment:** "Health professionals are reluctant to give a particular time frame in relation to prognosis due to the uncertain illness trajectory in liver failure."

---

- A few residents that were taking both drugs and alcohol were informed by St Mungo's staff of the high risks of overdose.
  - Denial of their high alcohol intake was common amongst residents.
- 

**Focus group comment:** "A number are warned not to drink anymore but they all have difficulty with this as they are so used to it, it is a habitual behaviour that they have no means of stopping."

---

- Residents frequently had to be reminded about GP and hospital appointments and information about their condition due to their memory problems.
- 

## Focus group comments

*"Many residents choose not to face up to the situation. This can be due to a prognosis of 'you will die if you do not stop drinking' not materialising – eg one resident told in the 1990s that he would die and he is still alive."*

*"These people do not just have liver problems, they have multiple health problems as well."*

*"The problem relates to the fact that residents can go down and down and then bounce back up again and their symptoms get better, it's peaks and troughs."*

*"Residents lead risky lives – have frequently had mates who die young."*

*"I would predict that clients would wish to contact their family but we do not see it. People are in denial and just keep on going."*

*"One resident looks awful, but has been like that for last two years – I have been arriving at work for a long time expecting to receive news of his death – but he is still alive."*

*"Very difficult to tell if they are at the end of life – some die, some seem to live for ever."*

*"Residents are not always aware that they are dying – some young ones dropped dead recently – they were completely unexpected."*

# Access to services in the community and within St Mungo's

## Key messages

- Interaction with GPs was predominantly for prescriptions
- Residents preferred to use a GP who specialised in the care of the homeless
- Residents engaged with internal services at St Mungo's such as key workers and substance misuse workers but rarely with mental health workers
- External services providing alcohol and drug advice support and information on treatment were sometimes accessed
- Residents were generally unwilling to accept support from social carers

## Supporting evidence

- The majority of residents (25/27) were registered with a GP - either a local or visiting GP to the hostel or a GP that they knew prior to living in the hostel. Two residents refused to be registered.

---

**Focus group comment:** "Residents have to get past the GP's receptionist and feel intimidated in the waiting room and so are unlikely to stay."

---

- From the limited information in the notes, 8/25 residents were documented as either not working with their GP or refusing to see them despite being registered. 6/25 had regular contact with their GPs - often to access prescriptions.

---

**Focus group comment:** "Some of our GPs are excellent and they will come to the hostels to see residents because we can't get them to go to the GP's surgery."

---

- The most frequent health professional visits to hostels were undertaken by GPs, practice nurses and community psychiatric nurses (CPNs). St Mungo's residents in a registered care home and a complex needs hostel received visits from CPNs, district nurses, community matrons, physiotherapists, chiropodists and podiatrists. Residents in semi-independent housing were often seen by occupational therapists and occasionally physiotherapists.
- Residents accessed various community health services providing outreach support for drug and alcohol problems, mental health problems and complex needs.
- The majority of residents received services from St Mungo's such as contact with a key worker, and a substance use worker. Two saw an intermediate care nurse, a complex needs worker and a multiple exclusion worker. There was little contact amongst residents with a mental health worker; some residents did not feel it was necessary to see one.
- A few residents did attend 'Lifeworks' - an internal psychotherapy service run by St Mungo's.
- There was no evidence that any residents were accessing social carers even though some residents were documented as being 'smelly' as they were not washing properly.

---

**Focus group comment:** "The personal hygiene of a client is abysmal - a real problem. However although the client was receiving a care package to help clean him he refused to accept it when he realised that he would have to make a financial contribution which he wanted to spend on drink."

---

- Two residents in semi-independent accommodation were accessing 'meals on wheels'
- Residents also used a number of external drug and alcohol services. Examples in this group include: an alcohol recovery project, alcohol resource service, Foundation 66, Equinox, Novo, Bench and Brighton Terrace that provides advice and support and referrals for treatment, detox and rehabilitation. The 999 club and the Mission provided social support.

## Focus group comments

*"Residents prefer to go somewhere where they feel comfortable ...even if it is a long journey. GP surgeries can be very intimidating for them."*

*"Some residents go to see a GP for the homeless in central London."*

*"Residents are more likely to access a GP within the project."*

*"Staff sometimes accompany residents to GPs to check that they are treated fairly."*

*"Some GPs are not willing to interact with residents who choose to keep on drinking."*

*"Difficult to get a continence service when booze related."*

*"'Lifeworks' was a beneficial psychotherapy service."*

*"They do not normally access services other than A&E, the benefits office and the off licence."*

*"They refuse social carers as they don't like being touched by anyone else.....more likely to trust staff or other residents."*

*"If a resident is unable to care for themselves we cannot care for them in the hostel, we would organise a nursing home or residential care bed."*



# Use of secondary care services

## Key messages

- Secondary care provided most of the health input for residents in the last six months of life
- Some residents attended multiple outpatient clinic appointments
- Residents often forgot or did not want to attend hospital clinic appointments
- Increasing frequency of emergency admissions in the last six months of life
- Residents often collapsed either inside or outside their hostel and were admitted to hospital; some residents self discharged as soon as they were well enough to walk away
- Limited evidence of communication between secondary care and hostel staff
- Residents reluctant to go to hospital as they were unable to abstain from drinking and smoking as required

## Supporting evidence

- Residents had appointments in a number of different hospital outpatient clinics. 12 residents had multiple clinic visits, seven of whom were attending three separate clinics in the last year of life.
- The specialist liver service (hepatology) was the most common outpatient clinic attended (nine residents), four residents were seen at Gastroenterology, 3 residents were seen at Cardiology, Anti-coagulant and Chest clinics, two residents were seen in Psychiatry.
- If a resident did not attend a clinic appointment and failed to let the clinic know the reason why, they were frequently discharged from the clinic.

---

**Focus group comment:** "Residents need constant reminding about clinic appointments. Staff accompany them and meet the doctor if the resident consents to this."

---

- 20 residents had 36 admissions during the last six months of life. The average total number of days spent in hospital was 18 days.
- The average number of days spent in hospital on the final admission was 9.5 days.
- Of the seven residents that had had no hospital admissions in the last six months of life, two had had a hospital admission at eight months but both self-discharged themselves. Four residents had been unwilling to engage with any health services at all and one had engaged with some services.
- In the last six months of life three residents discharged themselves from hospital following admissions for bleeding, ascities (fluid in the abdomen), vomiting and stomach pains.

---

**Focus group comment:** "Clients do not get good treatment, they do not want to stay in hospital and they do not want to hear what will be said."

---

**Case review:** One resident, who was receiving in-patient hospital treatment for end stage liver disease, kept walking out of hospital in the month before he died and returning to the hostel to check his funds so that he could access money to buy alcohol.

---

- Residents were sometimes reluctant to go into hospital for treatment. There was evidence in the case notes of two residents who refused to go in an ambulance. Equally there was evidence of reluctance amongst some ambulance staff to attend to particular residents.

## Focus group comments

*"Residents self discharge as soon as they can walk away. One resident turned up at the hostel in the middle of the night after self discharging."*

*"Hospitals generally don't like having our residents, they try to discharge them as soon as they can."*

*"We don't know what went on – just got a letter to say they self discharged – difficult to get results and information – rely on Cedars Road nursing team to get information (nurse to nurse)."*

*"It was so bad that we needed to create an intermediate care team. Patients were being booted out of hospital – equally they did not want to be there."*

*"Staff use the influence of other residents to persuade residents to go to hospital. They fear going to hospital."*

*"Staff realise that all is not well when a resident has increasing number of hospital admissions and the time in between these admissions decreases."*

*"Frequently have to wait for a resident to be so unwell that they have to go to hospital."*

*"They like to be free and don't like their behaviour to be controlled by others."*

---

**Case review:** Ambulance staff initially were reluctant to attend a call from staff at a hostel to assist a resident who had collapsed whose name was flagged up on the ambulance system as someone who was regularly being picked up off the street when drunk. St Mungo's staff had to persuade the ambulance to attend; the resident was finally taken to hospital where he died three days later.

---

- There was a lack of evidence in the case notes of information exchanged between hospital staff and St Mungo's staff about residents' medical condition (not possible without the consent of the resident), diagnosis and treatment. Only two discharge letters were found in the case notes. This lack of communication was confirmed by staff in the focus group meetings.

## Focus group comments

*“Secondary care is used predominantly for emergency admissions. They do not stay long – as soon as they feel better they want to leave – people from the streets want to do what they like.”*

*“Staff usually have to request discharge letters from hospitals.”*

*“Unfortunately there is no interim place where clients with greater medical needs who are discharged from hospitals can go to before returning to the hostel.”*

# End of life care and death

## Key messages

- Deaths of residents were often sudden
- The majority of deaths occurred in hospital
- Staff respected the wishes of residents to stay in the hostel when they were at the end of life for as long as it was possible to manage them
- Documented evidence of physical, psychological and behavioural symptoms in the days and weeks preceding a death
- Deaths in hostels were frequently related to drug and alcohol overdoses
- Some residents receiving treatment for HIV and Hepatitis C had severe side effects and deteriorated rapidly after stopping treatment
- Limited evidence of staff considering or attempting to access formal palliative care support
- There was no evidence of advance care planning within the case notes reviewed

## Supporting evidence

- The majority of deaths (19/27) took place in hospital. 10/19 deaths were sudden and had not been anticipated, three of which were drug and alcohol overdoses. Nine deaths were less sudden and followed an acknowledged deterioration in the resident's condition.
- Focus group comment: "Although the deaths may have been sudden, but when the whole situation was taken into account they were not entirely unexpected."
- Eight residents died in a St Mungo's hostel. Five were sudden deaths (four drug and alcohol overdoses, one from alcohol ingestion) and not anticipated. Three deaths were sudden but the residents had been in a poor state of health and their deaths were expected.

---

**Case review:** Residents' causes of death were documented as the following: seven were due to a drug and alcohol overdose, five to liver cirrhosis/failure, four to ischemic heart disease, two to pneumonia, two to heart failure, one to pulmonary TB, two to alcoholic cardiomyopathy, one to kidney failure, one to respiratory failure, one to head injury and one to natural causes.

---

17/27 residents had physical indicators such as jaundice, looking and feeling unwell and not eating; psychological indicators such as low mood and anxiety; and behavioural indicators such as binge drinking and aggression recorded in their notes - on average 14 days prior to death.

### Breakdown of overdose as the cause of death

Alcohol only = 9    Alcohol↔Drugs = 10    Alcohol→Drugs = 6    Drugs→Alcohol = 2  
Overdoses = 0    Overdoses = 4    Overdoses = 2    Overdoses = 1

- The average length of stay during the last hospital admission was 9.5 days prior to death.
- Two residents who received treatment for HIV and one resident who received treatment for Hepatitis C infection experienced severe side effects causing them to cease treatment. Following this they all entered a sharp decline in their health resulting in death in two cases within 11 days and in one within a month. One resident who started treatment for tuberculosis died four months later.

---

**Focus group comment:** "One of our residents went downhill really quickly after taking TB medication, his stomach became distended and he was admitted to hospital and he died very quickly from liver failure. Perhaps this could have been avoided if he hadn't started on the medication."

---

- Few examples of palliative care support recorded in the case notes.

## Focus group comments

*"Although clients have liver failure this is not always the cause of death."*

*"When they finally die they deteriorate very quickly."*

*"All the residents died in hospital but we try to keep them at the hostel as long as we can, when the resident is particularly keen to remain there as long as possible."*

*"More surprised that they are still alive!"*

*"They know they are living on borrowed time."*

*"Residents want to stay at home. Hostel facilities cannot always support residents to stay there."*

*"They definitely know when they are really ill - done with the denial part."*

*"Some residents were aware they were dying and some were not as they had been brought back from the brink so many times."*

*"Generally I think that residents do know deep down when they are deteriorating and in effect dying."*

*"We had one resident who was refusing to engage with us. We involved our Palliative Care Co-ordinator who went in and was able to work with him."*

# Implications for staff

## Key messages

- It was difficult for staff to determine when a resident was nearing the dying phase
- Many deaths occurred suddenly and had not been anticipated
- Staff were advocates for residents and tried to help them work with primary and secondary health care as well as with other services internal and external to St Mungo's
- Staff could be involved in resuscitation attempts including calling emergency services and clearing up after a resident's death
- Staff were often upset by the sudden deaths of residents
- Hostel staff sometimes became involved in supporting bereaved family members

## Supporting evidence

- It was not always clear to staff when was the right time to attempt to get the resident admitted to hospital at the end of life.
- Staff were often the first people to find residents in a state of collapse. They helped to contact the emergency services and were involved in the resuscitation of two residents prior to the arrival of the paramedics. Staff were also responsible for administering Naloxone (a morphine antidote) to one resident to try to reverse an overdose.
- If a resident died in the hostel, staff were involved in contacting the emergency services, the police, the next of kin and the coroner as well as writing a report about the incident and informing the other residents in the hostel.

---

### Focus group comment:

1. "We had a death at the hostel where somebody bled to death in their room ..... It was the staff who had to clear up afterwards."
2. "We don't always have a debrief after a death, which isn't great as staff need to talk about it, but sometimes it is not possible."

- 
- Staff were sometimes in contact with families of residents and tried to provide support to them after a death.

---

**Case review:** Following the death of one resident who was estranged from his family, the family began to visit the hostel after his death to talk to staff and his friends at the hostel about him.

- 
- There was no information in the notes about any advance planning for future care between staff and residents but it was documented when a resident was reluctant to go into hospital for treatment.

---

### Focus group comment:

1. "I involved the Palliative Care Co-ordinator from St Mungo's to help plan for one resident's death. It completely blew me away all the things that needed to be thought about eg wills, funeral, family wishes...."
2. One female resident visited her family and put personal possessions safely away for relatives three weeks before her death. Staff thought that this may not have happened spontaneously without the input of the Palliative Care Co-ordinator.
3. "I do get emotionally involved....I talk to my wife about it to try to make sense of what is happening at work."

## Focus group comments

*"They just want to be drinking. It is very hard to stand aside and watch someone drink themselves to death. We encourage them to try things but cannot force them."*

*"We get used to working with this high level of illness."*

*"We sometimes have to provide support to the resident, the other residents, the staff and the resident's family when they are on a downward trajectory and after death."*

*"It is a relief when a client goes into hospital."*

*"When you know someone is dying you question – is this good enough? Is this right?"*

*"Very difficult to stand back."*

*"Just lie in bed drinking – will not clear up their vomit."*

*"Staff occasionally wash a resident's clothes if they are in hospital or clear up their room for them when they return."*

*"A discharge from hospital can be a really stressful time for staff."*

*"Staff try to have conversations at different times of the day, to make sure that clients can make informed choices."*

*"Mobility will be a trigger for change in personal hygiene and state of their room."*

# Impact on other residents

## Key messages

- Residents recognised symptoms of jaundice and spitting blood as evidence of liver failure
- Residents could become involved in the care of fellow residents who were acutely ill and who were unwilling to work with community services
- The death of a resident did affect the other residents
- Relationships between healthier and sicker residents were complex and sometimes manipulative to gain access to further alcohol
- Residents could express envy or jealousy of increased attention for a dying resident

## Supporting evidence

---

**Case review:** One resident was surrounded by other residents trying to persuade her to go into hospital in an ambulance which she refused to do 10 days prior to her death.

---

**Focus group comment:** "Residents are more accepting of help offered from other residents, for example assistance with showering."

---

- Residents that were incapacitated would often get other residents to buy their alcohol for them.
- 

### Focus group comment:

1. "Social contact amongst residents is for the purpose of getting booze and drugs. Residents become more vulnerable to abuse."
  2. "One client was so desperate to get hold of booze that he still gave money to another resident for a second week although the resident had taken money from him the previous week."
- 

- When in hospital some residents received visits from fellow residents in the hostel who supplied them with alcohol.
  - One resident was so upset by the death of another resident that he claimed to have drunk seven bottles of sherry on the day of hearing of his death."
- 

**Focus group comment:** "When there is a death people are pretty shocked. They do not like others to die in the hostel. For a lot of clients it is facing their own mortality."

---

## Focus group comments

*"If a client is yellow (or green) this will be noticed by other residents. Physical signs are triggers for other residents rather than behaviours."*

*"When a resident starts to spit blood you know you have a problem. It is often the first sign that other residents notice and it rings alarm bells and often motivates them to encourage the resident to engage with health services."*

*"Residents will complain of the smell of incontinence and don't want those who had reached this state to be in common rooms."*

*"A tiny percentage resent not knowing what is going on, eg when taking a dying resident breakfast in their room, staff cannot explain the situation as it is a breach of confidentiality."*

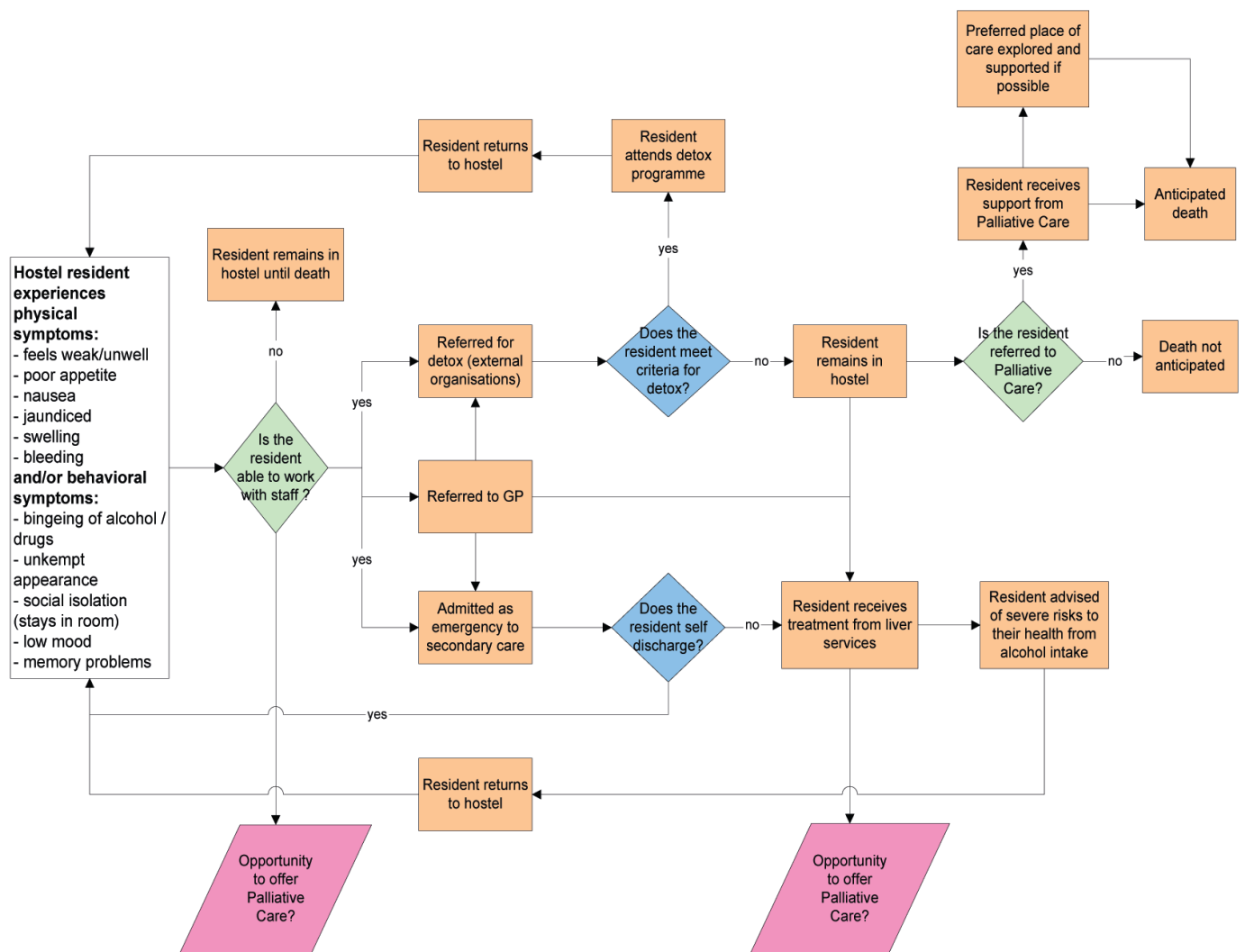
*"They see buying booze and visiting a poorly resident as nurturing."*

*"So many mates who are surprised when someone dies."*

*"Following a death the other residents will be quieter and a bit more respectful of staff."*

# Experiences of care for hostel residents with liver failure

• This flow diagram illustrates the possible experiences of homeless people residing in a hostel as their health deteriorates and death approaches. It attempts to suggest at which points there are potential opportunities to offer additional help and support including referral to palliative care. The options shown should be viewed in the context of respect for individual choice and autonomy.





## Discussion

In this research we have explored, in depth, case note records of the experiences of homeless people with liver disease whose health was deteriorating and who faced death, and talked with those who support them on a daily basis. Although our sample was small (n=31; one female), we were able to access all but four of the case-notes for our eligible group.

We have learned that there are some key physical and behavioural signs in homeless people with advanced liver disease that indicate that significant deterioration in their health has begun. These clues include worsening jaundice, spontaneous bleeding, low mood, social isolation and poor self care, and may be observed by professionals working with homeless people often within about two weeks of death. Some of these physical signs are indicative of clinical deterioration and may be seen more widely in populations with advanced liver failure. In addition, we cannot be sure whether the behavioural changes we observed might more generally occur in homeless people whose physical or mental health is deteriorating and are facing death from other causes. However, providing extra training and support for staff to recognise these physical and behavioural signs and act on them appropriately may enhance the experience of all sick residents as their health worsens towards death.

We know that many deaths appear to occur suddenly, but not entirely unexpectedly. By increasing the capacity of staff to be alert to key changes in health or behaviour we may optimise their ability to anticipate deterioration and death. This may provide opportunities for professionals to intervene to enhance the well-being of residents. For example professionals might consider attempting to offer additional psychological support, to facilitate meetings with significant family members or friends, to discuss with residents their preferences for care or to explore the possibilities for seeking medical interventions. In addition, as there is greater anticipation of likely deaths, there may be some benefits for staff in improving their own experiences of bereavement.

From the limited evidence available from the literature, we know that the problems faced by homeless people are often multiple and complex. Care must be considered within the context that many homeless people have survived difficult backgrounds, served in the armed forces or been in prison and find usual relationships challenging. There is some evidence that health professionals may harbour prejudices against homeless people for example due to their challenging behaviour, HIV or hepatitis C status or misuse of drugs or alcohol (Tarzian 2005). As a result, homeless people may be distrustful of those offering help. Earlier research has shown that homeless people frequently resort to accident and emergency services when their health has become critical (O'Connell 2005, DH 2010).

Any attempts to encourage homeless people to seek help must be tempered by respect for their personal autonomy and rights of individual choice. We know that many would value the opportunity to exercise more personal choice and express their wishes for care as their health deteriorates, for example in another study one group suggested the idea of a half-way house shelter to provide safe convalescence after discharge from hospital (Song 2007, 2008; O'Connell 2010).

We are aware of the resources available from the Department of Health *Route to Success* series ([www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)) and the work of the London Pathway ([www.londonpathway.org.uk](http://www.londonpathway.org.uk)) in NHS Trusts in north London. Although the London Pathway initiative is not limited to end of life care, our work provides further evidence to support its recommendations of encouraging both primary and secondary health care to work more closely with hostels and other community support organisations providing support to homeless people. New service developments should not be limited to London but extended to other areas of UK in which significant numbers of homeless people are found. St Mungo's and other charities working with the homeless are currently developing their services in several areas outside London.

There are inherent difficulties conducting research with people who are homeless, for example memory problems, issues of trust and confidentiality, and consent. However, by working closely with organisations involved in providing care and support to those who are homeless, in-depth qualitative research could be conducted. Research could explore directly with homeless people their wishes and specific needs for care towards the end of life, pilot new models of care and understand and test the acceptability and feasibility of ways to improve the skills of professionals working in this field. Further studies should include methods that enable a fuller understanding of the economic issues surrounding end of life care for those who are homeless.

Costs should be considered against the benefits to those who are sick, the potential savings of reducing hospital admissions, and the improved bereavement outcomes of staff, families and friends.



# Recommendations

We anticipate that the following recommendations could be realised rapidly:

- **Training for staff working with homeless people to provide support as health deteriorates and death approaches.** Hostel staff, such as key workers and substance misuse workers, who are in regular contact with their clients, are most likely to recognise when the physical condition and behaviour of a homeless person are deteriorating and the end of life may be approaching. Training would include learning to recognise the key physical and behavioural signs of change that may offer opportunities for interventions. Supplementary training in palliative care issues and communication skills could help staff feel more confident about talking to residents and supporting them as they reach this phase. Materials are currently being developed by the Palliative Care Co-ordinator and complement other initiatives such as the Department of Health *Routes to Success* document.
- **An end of life care resource pack for staff working with homeless people.** This would be aimed at increasing knowledge of health and social care needs of people in the last few months of life. It could include a fact sheet on signs and symptoms of liver disease and other life-limiting illnesses as well as general information on local end of life services that, with permission, staff could access for residents.
- **Access to bereavement support that acknowledges the challenges faced by staff and other residents in coming to terms with unanticipated deaths.** Staff and residents in hostels would benefit from extra support following the death of a resident. A system of debriefing discussions may be beneficial. Educational sessions on loss, bereavement and grief would enhance the ability of staff to support other homeless people who are affected by a death, as well as family and friends of the deceased. Staff may also feel empowered to raise in a more timely fashion issues of end of life care with homeless people whose health is deteriorating.
- **Maintenance of the role of the Palliative Care Co-ordinator** and its extension to other sites to support the implementation of these recommendations.

In the longer term we would like to plan the following further research:

- In depth qualitative work directly with homeless people to explore their needs and current experiences of health and social care as their health deteriorates
- The development and testing of new service configurations to improve these experiences
- An in-depth understanding of the economic costs and benefits of new approaches including the effects of reducing hospital admissions and enabling death in usual place of residence
- Work on innovative solutions that might include a half-way house facility that provides holistic care to homeless people with a range of chronic and life-limiting conditions and could complement other ways of bridging the gap between primary and secondary care.

## Key references

O'Connell, J.J., December (2005). Premature Mortality in Homeless Populations: A review of the literature *National Health Care for the Homeless Council*

O'Connell M, KasproW W, Roenheck RA (2010) National dissemination of supported housing in the VA: model adherence versus model modification. *Psychiatr Rehabil J.* 2010 Spring; 33(4):308-19

Department of Health Office of the Chief Analyst. (2010) Health Care for Single Homeless People 22 March. London: Department of Health

Podymow, T., Turnbull, J., Coyle, D., (2006). Shelter-based palliative care for the homeless terminally ill *Palliative Medicine* 20: 81-86

Spencer, L Ritchie, J O'Connor, W (2003) 'Carrying out Qualitative Analysis' in Ritchie, J Lewis, J (Eds) *Qualitative Research Practice* London: Sage

Route to Success Series found at [www.endoflifecare.nhs.uk/routes\\_to\\_success](http://www.endoflifecare.nhs.uk/routes_to_success)

Song, J., Bartel, D., Ratner, E., Alderton, L, Hudson, B., Ahluwalia, J., (2007). 'Dying on the streets: Homeless Persons' Concerns and Desires about End of Life Care' *Journal of General Internal Medicine* 22: 435-441

Song, J., Wall, M., Ratner, E., Bartels, D., Ulvestad, N., Gelberg, L., (2008). 'Engaging Homeless Persons In End of Life Preparations' *Journal of General Internal Medicine* 23(12):2031- 2045

Tarzian, A., Neal, M., O'Neil, A., (2005). 'Attitudes, Experiences, and Beliefs affecting End of Life Decision Making Among Homeless Individuals' *Journal of Palliative Medicine* 8(1).

The London Pathway [www.londonpathway.org.uk](http://www.londonpathway.org.uk)



**Partnership organisations for this project:**

St Mungo's

[www.mungos.org](http://www.mungos.org)

Marie Curie  
Cancer Care

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

Marie Curie Palliative  
Care Research Unit  
University College  
London

Registered under the Industrial &  
Provident Society Act No. 20598R  
Registered with the Housing  
Corporation No. LH0279

Marie Curie Cancer Care Charity reg no. 207994 (England & Wales),  
SC038731 (Scotland) P363