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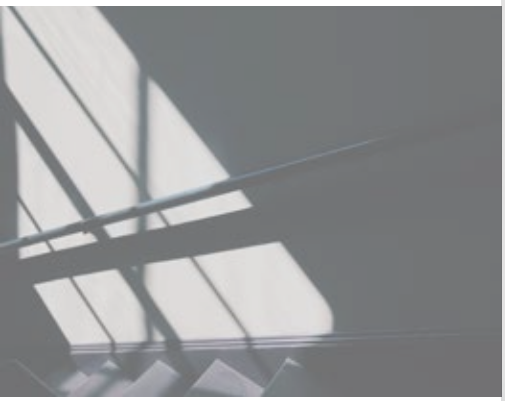


How can we avoid treatable or preventable deaths

of people facing multiple disadvantage?

Fulfilling Lives
South East Partnership

bht sussex

COMMUNITY FUND

CONTENTS

EXECUTIVE SUMMARY

As a legacy to Fulfilling Lives South East (FLSE), this report highlights the deaths of people facing multiple disadvantage who were supported by FLSE over the past seven years. The report focuses on those clients who died from treatable or preventable causes, if they had received earlier intervention.

Firstly, we consider some of the reasons why people facing multiple disadvantage are at such a high risk of premature death. From the 12 clients who died (out of a 118 total caseload), our data (from death certificates) finds that six clients died of non-communicable diseases (NCD) in hospital. All of these clients died from alcohol and substance related diseases. Secondly, our case studies demonstrate that childhood trauma and neglect often continue into adulthood, linked to an increased risk of physical and mental health problems. Thirdly, our case studies of the clients who died from 'natural causes', as well as our wider caseload, emphasise the barriers faced in the existing healthcare system by people with multiple and complex needs (MCN).

A healthcare professional provides insightful reflections, not least that earlier interventions could have slowed down or prevented premature deaths of people with MCN for some of her patients.

OUR REPORT CONCLUDES THAT:

- healthcare access is **restricted** and often inadvertently excludes people with MCN
- **women** are disproportionately affected by complex needs and related premature death
- people with MCN experience **stigmatising practice** and **negative hospital experiences** because of a system which does not recognise trauma and multiple disadvantage

OUR KEY MESSAGES ARE:

- **Community-based healthcare** and earlier intervention for people facing multiple disadvantage **saves lives and reduces costs.**
- People with MCN face barriers accessing healthcare.
- **Third sector non-clinical assertive outreach is not enough**, particularly for physical and mental health needs.

INTRODUCTION

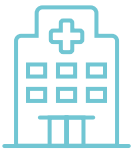
Individuals facing multiple disadvantage are more likely to experience premature death compared with the general population (Aldridge, 2018). With some of the most complex cases, Fulfilling Lives South East (FLSE) had the highest mortality rate across the national programme. Restricted access to healthcare is a recurring theme in our casework; client data signals that many clients have multiple long-term chronic conditions and female clients have more complex and chronic conditions compared to men.

We know from our project's work that there are high levels of repeat attendance at A&E for FLSE clients. The highest attendance for a client who died on our caseload was 22 A&E attendances over a three-year period, with 12 attendances in one year as a maximum. Across the whole FLSE caseload, A&E attendances were even higher with one client attending A&E 44 times in one year and other clients attending between 20-33 times within the space of one year. Healthcare services are often unable to meet the needs of clients experiencing multiple disadvantage, without significant intervention from support workers.

OUR CLIENTS' EXPERIENCES:

- Problems accessing GP and outpatient appointments.
- Lack of joined-up services, without processes in place for healthcare services to communicate with agencies supporting clients, especially on discharge from hospital.
- Stigmatising practice.
- Severely restricted access to healthcare services, because of being put on the 'Special Patients Scheme', for clients who have had a previous violent or aggressive episode in a healthcare environment (now under review by Healthwatch).

A healthcare system which does not meet the needs of people experiencing multiple disadvantage also comes at a high financial cost. From the information we could establish about costs of medical appointments for all our 118 clients (calculated with the Greater Manchester Combined Authority Research Team tool), based on an average yearly caseload of 47 clients, the highest annual levels were:



A&E ATTENDANCES

141 attendances, costing **£23k**

44 separate attendances by an individual, costing **£7k**

HOSPITAL INPATIENT STAYS

126 days, costing **£130k**

73 days in total by an individual client, costing **£76k**

MENTAL HEALTH HOSPITAL INPATIENT STAYS

632 days, costing **£271k**

92 days in total by an individual client, costing **£39.5k**

The total highest annual average for all three medical services above, based the average caseload of **47**, was **£170.5k**. This amounted to **£3.6k** per person per year.

Our client work and collaborations with local agencies has indicated that community-based healthcare and earlier intervention for people facing multiple disadvantage could potentially save lives, ensure their needs are better met, thus reducing healthcare costs (see examples in sub-section 2.4).

FLSE's report responds to Making Every Adult Matter's (MEAM) recommendation in their recent review, to initiate and develop local review processes for these tragic and needless deaths of people facing multiple disadvantage.

As highlighted in the Chief Medical Officer's Annual Report 2021 which focuses on deprived coastal communities, the wider determinants of health are the most significant factors influencing health outcomes (80% according to NHS research). These include education, housing, transport, and leisure. There is also a need to provide more coordinated joined-up care for an increasing number of people experiencing multiple and complex needs (MCN), which works around their needs, not within organisational silos. FLSE operates in Brighton & Hove, Hastings and Eastbourne and strongly supports Prof. Chris Whitty's conclusions that health problems of coastal communities must be dealt with at national, regional, and local levels. By improving the health of coastal communities, the median health and wellbeing of the national population would be significantly improved. FLSE supports the latest **population health** approach, in line with Prof. Whitty's report, to reducing health inequalities through a **holistic integrated care system.**

OUR REPORT HIGHLIGHTS:

- Some of the reasons why, in our experience and from recent research, people facing multiple disadvantage are at such a high risk of premature death.
- Analysis of FLSE's data on clients who died prematurely in hospital, supported by case studies.
- Insights from a healthcare professional.
- Recommendations for future action.

1. OUR APPROACH

We collated and analysed data on the 12 out of 118 clients who died whilst on our caseload. We decided to focus on the seven clients who died in hospital, as six of these clients died from treatable and preventable causes had they received earlier intervention. The deaths of these clients were not investigated as they were considered to be from 'natural causes' (compared with the five sudden deaths at home which involved an inquest).

We gathered and analysed data and case studies of our clients who died; supported by wider data and casework from all our clients, and a reflection from a healthcare professional with an inside perspective.

According to MEAM's report, recent research suggests there is a certain 'normalisation of death' amongst local communities who face multiple disadvantage due to the high mortality rate within their peer group. We want to highlight this attitude as it should not be accepted as the norm, and such high mortality rates at such a young age need to be investigated. Our analysis presents an opportunity to create change and prevent this in future.

In this report, we use the internationally recognised definition of 'preventable mortality', developed by the Organisation for Economic Cooperation and Development (OECD), which is: "deaths that can be mainly avoided through effective public health and primary prevention interventions". 'Treatable (or amenable) mortality' is defined as "deaths that can be mainly avoided through timely and effective healthcare interventions, including secondary prevention and treatment".

2. OUR ANALYSIS

2.1 HEADLINE FACTS

FLSE's key data:

13% of FLSE clients died (12 out of 118) compared with **6%** nationally (an average of 18 client deaths out of a 339 average client caseload for similar national MCN programmes)

50% of FLSE caseload (6 clients) died in hospital from natural causes connected to substance and alcohol misuse

Only 14% of deaths in hospital from natural causes (1 client) required an inquest, compared with **100%** for sudden deaths at home (6 clients)

2.2 CAUSES OF DEATH

Table 1 sets out the primary causes of death for all 12 clients (in bold), as well as any contributing factors listed beneath.

TABLE 1 CAUSES OF DEATH FOR FULFILLING LIVES SOUTH EAST CLIENTS

INQUEST NOT HELD	INQUEST HELD
HOSPITAL DEATHS	NON HOSPITAL DEATHS
End stage decompensated alcoholic liver disease Chronic pancreatitis, cerebral atrophy	**Fatal toxicity of heroin** Anxiety
Hypoxic brain damage, cardiac arrhythmia with cardiac arrest, cirrhosis of the liver Steatosis of the liver	**Hanging** None
Multiple organ failure, Cirrhosis of the liver and pneumonia None	**Hypovolaemic shock, Intra-abdominal haemorrhage, Traumatic splenic laceration** Liver cirrhosis
Sepsis of unknown origin Chronic liver disease, chronic pancreatitis	**Mixed drug toxicity** None
Sepsis, Bronchopneumonia Intravenous drug user, acute kidney injury, metabolic acidosis	**Small intestinal ischaemia and multiple drug toxicity** Intestinal adhesions
Spontaneous bacterial peritonitis, decompensated liver cirrhosis None	HOSPITAL DEATHS
	Methadone toxicity None

From the 12 clients who died:

- **Seven clients died in hospital** from **preventable or treatable causes** if earlier intervention had been made.
- **Six out of seven clients** who died in hospital **did not involve an inquest** and so no local authority review was undertaken regarding their deaths.
- For all **seven** cases, contributing factors were diseases related to long term alcohol and substance use.

The World Health Organisation uses three main categories for causes of death:

- ***Non-Communicable*** including heart disease, stroke, cancer, diabetes, chronic lung disease and mental health conditions.
- ***Communicable*** which are infectious or transmissible diseases.
- ***Injuries.***

All our clients who died from natural causes in hospital were because of **non-communicable diseases (NCD) and conditions.** This forms part of a global rise in NCD, responsible for **70%** of deaths worldwide, as a result of tobacco use, physical inactivity, the harmful use of alcohol and unhealthy diets.

2.3 LEARNING FROM FLSE CLIENTS

Our case studies on all clients demonstrate that childhood trauma and neglect perpetuate into adult life and can often lead to self-neglect of mental and physical health needs. A total of 338 highly complex individuals were referred to FLSE throughout the project between 2015 – 2021. Out of 118 clients who were taken onto the FLSE caseload, 75% (88 clients) had a disability. The most common disability was mental health problems (84%), followed by progressive and chronic illness (26%) and issues with mobility (26%). In total, 80% of clients on the caseload reported suffering from physical health problems, often multiple issues. The top five most common health issues experienced related to bones and joints, liver conditions, dental problems, skin/wound infections, breathing problems and chest pain.

Our data and case studies from the clients who have passed away clearly demonstrate significant and disproportionate health concerns, compared with the general population. For example, 22% of the UK's population reported a disability in a recent UK government survey (2019-20), compared with 75% of our clients. Such a high level of disability, as well as progressive and chronic illnesses puts people with multiple and complex needs at a distinct disadvantage in a healthcare system designed to cater for the majority. Recent studies indicate that people with multiple and complex needs, as well as people with disabilities, often have lower quality of life, increased risk of premature death, and may need considerable NHS support. The Health Foundation found that the healthcare system is hampered by a lack of information about the conditions that people have and their existing care arrangements or contact with healthcare services. From our case studies, this report highlights several barriers faced by people with MCN, which mean that they experience exclusion from the healthcare system.

The three main themes which arose from our analysis were:

- **Restricted healthcare access**
- **Lack of women's healthcare,** and
- **Negative hospital experiences**

2.4 RESTRICTED HEALTHCARE ACCESS

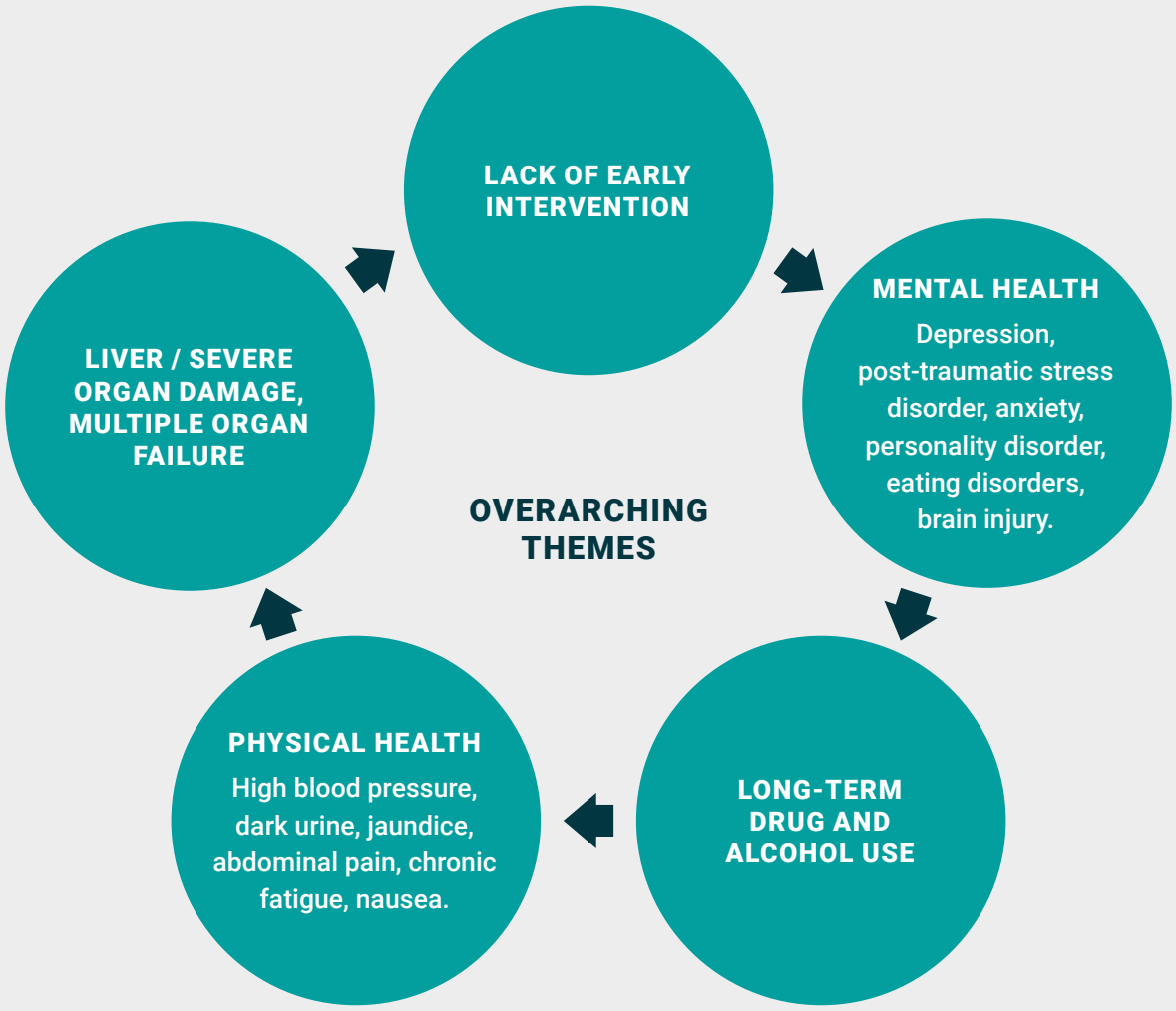
Our data reveals that the clients who passed away in hospital from natural causes had a markedly higher attendance at A&E in the time leading up to their deaths, compared with those who died suddenly. This would suggest that the clients who died in hospital were attempting to engage with healthcare services, particularly for their physical health.

However, our case studies of the clients who died from natural causes demonstrate that they faced several barriers to accessing primary and secondary healthcare. These include a lack of flexible, joined-up services, eligibility criteria and past experiences which deterred or prevented clients from accessing treatment.

Diagram 1 below demonstrates how our clients' causes of death can spiral from a lack of early intervention by healthcare and other services.

> ***"I'm really scared that I will end up not capable of speaking and losing my eyesight. I really want to get to appointments but will need reminding".***
>
> FULFILLING LIVES CLIENT

DIAGRAM 1
OVERARCHING THEMES OF CAUSES OF DEATHS OF CLIENTS ON FLSE PROGRAMME 2015 – 2020



These are specific examples of the barriers faced by clients who died from natural causes in hospital:

BARRIER	REASON / CIRCUMSTANCES
Difficulties travelling to hospital.	Reliant upon abusive and controlling partner for transport to hospital to treat and manage a chronic condition (Hepatitis C).
Inflexible appointment times.	Appointments for vital Hepatitis C treatment only available once a week, at set times. The client had problems with time management, due to homelessness and active addiction. Only 3 appointments attended, with significant support from a FLSE worker. Client dropped out of contact as she lost her mobile phone, and the hospital could not deliver messages easily.
Lack of knowledge about treatment.	Client had a lack of knowledge about her treatment for Hepatitis C and had fears it would be like chemotherapy, as she was reliant on street community for her knowledge around this.
Fear of GP and hospital appointments, due to past experiences.	Client A stated that she hated hospitals and found the appointments really challenging. Client B had problems waiting in reception for GP appointments and at A&E, when intoxicated and due to a controlling partner. She often left without treatment. Client C actively avoided going to the GP but agreed to have his blood pressure checked at a drop-in service, after which he started to visit the GP. The nurse, receptionist and GP all took a person-centred approach and were non-judgemental. The client started to visit twice a week and even arranged some of his own appointments. However, he became too unwell and decided to stop attending just before he died.
Lack of eligibility for healthcare services.	Client who could not manage her physical health was recommend by the Multi-Disciplinary Team to an out-of-hospital team. However, the client was not accepted due to her drug misuse. She was referred to a 'High Risk User' clinic, for which the post was not yet in place.

Third sector non-clinical assertive outreach (as modelled by FLSE and other programmes) was not able to solve the healthcare barriers listed in the table above. Whilst assertive outreach for people with MCN can yield significant improvements in areas such as drug and alcohol, housing, prison release and domestic abuse, there is less evidence to demonstrate much improvement in physical health.

From our data, using the **Homeless Outcomes Star™** tool which measures the strengths and support needs of people using homelessness services, **physical health** scored the (joint) lowest level of improvement over the time clients were on the programme. On average, clients improved in every other area and **emotional and mental health** was the third least improved area.

2.5 LACK OF WOMEN'S SPECIFIC HEALTHCARE

Our data found that:

- Of all the Fulfilling Lives South East clients who died in hospital of preventable or treatable conditions; **75%** were women (6 clients), compared with **25%** who were men (one client).
- Of all the FLSE female clients who died, **100%** were from preventable or treatable causes in hospital, without inquest or further investigation.
- The average age when clients died was **slightly higher for women** (42 years), compared with men (41 years).

What does this mean about healthcare for women who face multiple disadvantage? As women, do they experience additional levels of health inequalities?

Our project believes that women facing multiple disadvantage are more likely to have more complex health issues and are more at risk of premature death. Our client work suggests the healthcare system struggles to meet their needs even more so than men facing multiple disadvantage. Our case studies below highlight the complex trauma experienced by women who received support from across FLSE, culminating in very complex health needs. This evidence clearly illustrates why women's specific healthcare services are paramount and could ultimately reduce or prevent premature deaths of women facing multiple disadvantage.

CASE STUDY: COMPLEX HEALTH

Bella had been using alcohol and substances including class A drugs daily from a young age due to childhood abuse and early traumas contributing to poor mental health, self-harm, and suicidal ideation. Bella had significant, long, and enduring health needs, including epilepsy, COPD and Hepatitis C. During her last years, Bella was a patient under the Special Allocation Scheme (SAS) at her GP surgery. Whilst this meant there were limitations on when appointments could be scheduled, Bella appreciated the extra time to explain her concerns and complexity of her health issues.

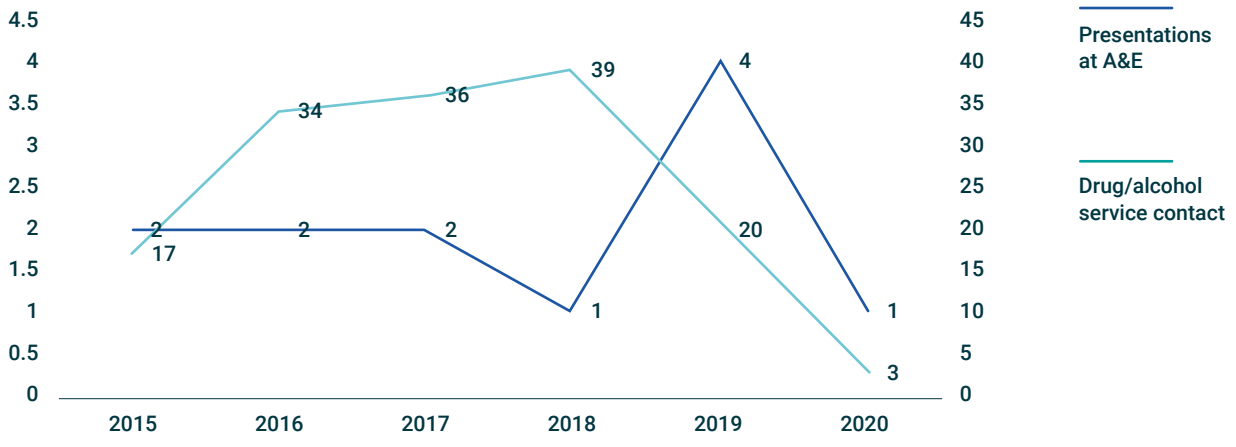
There was real difficulty in getting a 'balance' for Bella and her healthcare due to the active addiction, insecure housing, abusive relationship, complexity of her medications and physical issues. Bella was classed as needing palliative care by the SAS GP.

Bella said that she wanted to engage with her treatment but found hospitals very challenging and it was almost impossible to make appointment times due to being homeless and in active addiction. We might reflect on the complexity of Bella's different health issues, and whether there was a clear treatment pathway for health professionals to follow given her other, more pressing, support needs (e.g. housing and addiction). To put this in context, Bella attended six hospital appointments and was hospitalised three times in the last two years of her life. During the five-year period of FLSE support, Bella had 149 contacts with substance misuse services (averaging 7.8 contacts per quarter) and four presentations at A&E in the year leading up to her death (12 in total over the five-year period).

We might reflect that to treat and support a client like Bella there needs to be an incredibly robust multi-agency disciplinary approach which is often marred by the clients' disengagement due to their complexities. A multi-agency approach that would work flexibly with complex clients, not discharging MCN clients upon missed appointments which often lead to cancellations of referrals to specialist treatments.

Bella sadly passed away suffering from many complex physical issues in her early 40's.

BELLA'S PRESENTATIONS AT A&E AND DRUG/ALCOHOL SERVICES



CASE STUDY: SEEING PEOPLE THROUGH A TRAUMA LENS

Robin is an amalgamation of typical childhood history of the women supported by FLSE, all of whom experienced complex traumas from a young age and are often misunderstood in their behaviours. Robin grew up in a low-income family with both parents experiencing mental health and substance addiction struggles. Witnessing regular Domestic Abuse, strangers and her parents using drugs in the house, experiencing being abused, neglected and often hungry as food supply was sporadic. Robin and the little brother she had to care for, did not feel safe and felt they did not have a 'home'.

At school Robin was often falling behind and would be in trouble for daydreaming and being unable to concentrate, given punishment and told she was rude and lazy. Robin's behaviour is a classic example of how trauma presents in children and more needs to be done to educate our society in identifying trauma in order to get the necessary help and essential early intervention.

When Robin was badly beaten by her dad leading to being hospitalised, social services became involved, but she remained in an unsafe, scary, and un-nurturing home. Robin became a looked-after child following sexual abuse she experienced under her parents' care, moving around a lot due to behavioural issues and told she was unmanageable.

Due to the traumas and neglect throughout her life, Robin was now moving in circles where she was made to believe she was being loved and cared for by being given attention and gifts. Robin felt important, but it left her open to exploitation, being introduced to class A drugs and groomed into sex work.

Robin entered several abusive relationships after leaving care and started living in a homeless hostel, not engaging with staff, disobeying the rules, and often being evicted from accommodation. Suffering from poor mental health, psychosis, and numerous suicide attempts, a referral to mental health services was unsuccessful as her active substance use meant she did not meet the complex criteria to access this support.

Many services discontinued attempts to support Robin as she was either too hostile to work with or didn't engage, leaving Robin feeling helpless and stuck. Robin was referred to FLSE by other services as a last resort to engage in support. FLSE were able to offer tailored, trauma-informed, and flexible support, enabling Robin to learn how to form healthy relationships and attachments, essential to learning how to relate to others in a positive way after experiencing severe neglect and trauma.

Throughout FLSE's work, our client facing workforce had regular access to clinical supervision, enriching the workers' knowledge of traumas and being able to see clients through a 'therapeutic lens'.

2.6 NEGATIVE HOSPITAL EXPERIENCES

Our case studies suggest that healthcare services can sometimes be stigmatising in their language and practice and lack the processes to communicate effectively with agencies who are supporting the client. Healthcare services are often unaware of trauma presentation and unable to support the specific needs of long-term alcohol and substance use.

In the general population, people with multiple co-occurring long-term health conditions usually access several designated clinics to manage their health. Whereas self-neglect from early childhood trauma means that the FL client group rarely prioritise their health needs and rely on scarce GP appointments or on A&E to address urgent or emergency care.

Examples of negative hospital experiences witnessed by a FL Specialist Worker, for the clients who died in hospital include:

Client with multiple chronic conditions presented at A&E three times within a 6-month period and each time was told she had been given "life-saving treatment". A safeguarding adult nurse stressed the need for multi-agency working in discharge planning and a FL specialist worker was asked to be contacted before discharge. However, **the client was always discharged without any notification.**

After reading she had alcohol related liver disease the consultant said, "I will see her at some point, but I have other people to see who are very poorly".

Regarding stronger medication I heard a consultant say, "give her whatever, give her anything". [A client dying from liver disease].

Regarding basic support needs for a client, one nurse was very abrupt and did not show any patience when the client was struggling to stand up, did not have time to support the client to the toilet and the commode wasn't easily available (only one per ward), had to request water daily for the client and was offered food even though there was a 'Nil by mouth' sign above her bed. [A client who was experiencing ongoing domestic violence, suffered mental health issues, severe liver disease and pancreatitis].

These examples demonstrate the need for a system where people with MCN who enter hospital are given support that meets their multiple needs, particularly regarding discharge and follow-up care needs.

3. OUR RESPONSE

In this section we will highlight some of the initiatives that FLSE has taken forward at a local, regional, and national level to address the health inequalities raised in our analysis of clients who died from preventable and treatable causes in hospital.

3.1 IMPROVING PRIMARY HEALTHCARE ACCESS

FLSE's Bright Spots project is committed to improving access to, and coordination of, primary care to better address the needs of people experiencing MCN. The aim is to understand what 'good' providers of primary healthcare are doing to unlock better outcomes to inform and influence other services and key decision makers. The FLSE subgroup identified some services as 'good' providers, including ARCH Healthcare, St John's Ambulance, the East Sussex Rough Sleeper Initiative (RSI) Project and Seaview Project.

Following interviews with these providers about their work to support people with MCN, some of the group's main findings were:

- Drop-ins are the preferred way for people experiencing MCN to access healthcare support followed by outreach and text messages.
- Lack of stigma from staff is key to establish human, kind and trusting relationships.
- Multi-disciplinary approaches and meetings across services are necessary to provide the holistic support that patients need, including healthcare support.
- Experts with lived experience need to be included when starting to set up new services to inform operating principles and practices.

The **top 3 tips** to improve health services for people with MCN are:

1. providing services in a flexible way.
2. a collaborative approach between services (not just signposting).
3. investment in staff training and resources.

Providers of effective services offered staff training in the following areas:

- mental health first aid
- trauma-informed approaches
- housing, debt, and benefits advice
- Substance misuse problems

3.2 IMPROVING WOMEN'S SPECIFIC HEALTHCARE SERVICES

In June 2021 FLSE fed into the government's 'Women's Health Strategy Review'. It was recognised by the Secretary of State for Health and Social Care that, "For generations, women have lived with a health and care system that is mostly designed by men, for men."

In response, we recommended support for:

- Women only spaces in healthcare settings, such as sexual health clinics.
- Specialised healthcare services for women with MCN.
- Making appointments should be flexible (not only online or phone) and offer walk-in clinics.
- The frailty score should be used for women (and men) with MCN to offer healthcare services more quickly, using the 'Edmonton Frail Scale' (Rolfson et al., 2000).
- Making trauma-informed approaches training compulsory to all healthcare professionals.
- Improved coordination of support services for those with comorbid mental health and substance misuse conditions.

3.3 IMPROVING HOSPITAL EXPERIENCES

FLSE is collaborating with the Homeless and Inclusion Health Specialist Service (together with partners) in Brighton on an Intermediate Care Step Away Project - see Homeless Health Inclusion Team (sussexcommunity.nhs.uk).

The **Intermediate Care Step Away Project** is committed to ensure that when people with MCN enter hospital, they will experience support that meets their multiple needs and that they consistently experience a discharge that includes the follow-up community care needed. The main aspects of the service are outlined below:

- Provides holistic outreach services for homeless patients after being discharged from hospital to a unit within a Brighton homeless hostel for up to 12 weeks in the community, acting as a bridge to patients who would otherwise not be able to get care in the community once discharged.
- Involves a multi-professional team, from advanced nursing and allied health professionals such as occupational therapists (OT's), physios and psychologists who will provide a holistic approach to homeless care not only by providing physical, psychological, and emotional support but also by linking patients into other healthcare pathways.
- Targets people who are currently or are at risk of rough sleeping, frequent users of urgent and emergency care, those readmitted; and patients with a history of rough sleeping who need safe and timely continuity of care from hospital or reablement.
- Works with individuals towards self-management of their health conditions, reestablishing life skills through targeted therapeutic interventions and encouraging functional independence.
- Aims to decrease hospital admissions and increase the quality of life for this patient group, in the long-term.
- Monitors the frailty of patients using certain measuring tools including the 'Edmonton Frail Scale', as defined below, to demonstrate the need for a specific 'one stop shop' model, like the geriatric clinics provided already. Recent research (Pathway, 2020 and King's Fund, 2020) evidences that people with MCN aged between 30 to 50 years are experiencing very poor health outcomes and chronic long-term conditions, more associated with elderly people.

EDMONTON FRAIL SCALE (EFS)

Edmonton Frail Scale (EFS) provides an overall score by assessing fitness and frailty of an individual along a continuously graded scale. The EFS uses a five-level scale (ranging from 0-5 for 'not frail' to 12-17 for 'severe frailty') to measure the individual's cognition, general health status, functional independence, social support, medication use, nutrition, mood, continence, and functional performance.

We hope that the Intermediate Care Step Away project will create a more streamlined pathway for homeless people from admission through to discharge from hospital and into community-based support. Having a more streamlined pathway will ultimately improve healthcare for homeless people in the city, decreasing re-admissions.

4. REFLECTIONS FROM A HEALTH PROFESSIONAL

We asked Caterina Speight, Clinical Services Manager and Nurse Lead, Sussex Community Foundation NHS Trust, Homeless Inclusion Health Team, how she thought the healthcare system could be improved to prevent deaths of people facing multiple disadvantage.

In Caterina's experience, there have been some patients she has worked with over the years where earlier interventions could have slowed down or prevented premature death of people with MCN. For example, by recognising patterns of deteriorating health or lessening engagement with primary and/or secondary healthcare services to diagnose conditions and prevent disease progression.

> ***"For some, however, the idea of going into hospital for any investigations or diagnostic assessments is too much. They have either felt, or have been, judged harshly by professionals who see their addiction first and not the person. They may have past trauma resulting from living or growing up in various institutions".***
>
> **CLINICAL SERVICES MANAGER AND NURSE LEAD, SUSSEX COMMUNITY FOUNDATION NHS TRUST, HOMELESS INCLUSION HEALTH TEAM.**

Some of the key areas for improvement which Caterina has identified in her work include:

Having a single trusted healthcare professional or keyworker in the community to help people with MCN to attend appointments, which can often be chaotic or frightening for them.

Rapid Access Clinics which would allow people with MCN to be treated in one day for a range of different conditions, overseen by one consultant to help create trust and encourage engagement.

Educating frontline workers to recognise signs and symptoms of patients deteriorating to help prevent their conditions worsening or to support with palliative care where needed. This work has already begun.

Ultimately, deterioration of health for people with MCN could be prevented from moving into an advanced ill health state through earlier interventions into a more trusted environment, diagnostics with good follow-up and triaging people with MCN directly to the right clinical services in the community.

5. CONCLUSIONS

People with MCN face significant health inequalities, much higher levels of premature death and are far more likely to suffer from long-term physical and mental health conditions than the general population.

Our data demonstrates that overall FLSE clients improved in all areas of their strengths and needs with specialist support, measured with the Homeless Outcomes Star tool but not as much as we had hoped in the areas of physical and mental health. Our assertive outreach workers have been able to register all clients with a GP during the time they were supported by FLSE and supported to engage with other specialist services. However, even with this support, our data, using Homeless Outcomes Star, indicated that physical health was the least improved area for individuals with MCN, closely followed by emotional and mental health, owing to structural disadvantages. This is backed up by the Chief Medical Officer's recommendations, based on the report's conclusions that deprived coastal communities in East Sussex face structural disadvantages and as such, have higher numbers of individuals experiencing MCN.

Even when really in need of medical treatment, people with MCN struggle to access it due to complex trauma experiences. Some of the reasons include fear of being around others due to domestic abuse, mistrust of public services after removal of children from their care, experiences of stigma with alcohol and drug addictions, memory impairment, depression, suicidal thoughts, chronic self-neglect, and anxieties resulting in isolation from support networks.

Adverse Childhood Experiences (ACE) increase the risk in adulthood of chronic diseases. According to recent research, an increased level of ACEs is linked to the development of heart disease, cancer, chronic lung disease, and diabetes. Multiple adverse experiences in childhood are also linked to unintended pregnancies and being a victim or perpetrator of violence. When people with MCN do present at acute or primary care settings, they are likely to need urgent medical attention. To encourage and engage people with MCN in treatment and management of their healthcare needs requires a healthcare system that offers flexibility, joined-up services, and greater awareness of trauma-related conditions. The analysis in this report clearly demonstrates the need for Integrated Care Systems (ICS) which are designed to coordinate the organisations which provide health and social care across an area, including NHS, local councils, and other key partners in the voluntary and community sector. The aim of working together to improve healthcare and reduce inequalities between different groups will help ensure patients experiencing MCN are rapidly triaged to the right support pathway. We are pleased to see that the ICS in Sussex now has a trauma-informed workstream, in recognition that trauma has the effect of limiting a person's ability to interact with care.

This study on the clients who died, albeit based on a relatively small sample, appears to indicate that women are at a significantly higher risk of premature death from preventable or treatable causes then men. This finding is also reflected across the whole FLSE caseload, with women reporting consistently higher levels of physical health problems than men. This study found that access to A&E increased considerably for women with substantial support from FLSE, compared with most of the men who died on the FL caseload from accidental or sudden causes. Nonetheless, these interventions were too late and could not fully address the complex and often advanced health and social care needs without immediate and full support across all services and agencies involved. The case studies highlight the additional complexity of women's needs, particularly around domestic abuse, sexual trauma, and unsafe accommodation, exposing certain gaps in services for women. The healthcare system needs to offer women-only spaces in healthcare settings, greater flexibility for appointments without risk of losing healthcare access, a non-judgemental and trauma-informed approach by healthcare professionals and specialised women's healthcare services.

The negative hospital experiences highlighted in this analysis, including the lack of processes to communicate with agencies, present the demand for a robust multi-agency approach for people with MCN, as hospital in-patients and in their discharge planning. This should ensure ongoing health and social care needs are met so repeat returns to A&E can be avoided or significantly reduced. Stigmatising practice in healthcare settings calls for a system which prioritises multiple disadvantage and trauma training for health professionals, and the well-established links between trauma, alcohol & substance misuse, and behavioural issues. These systemic changes would significantly improve the experiences of people with **MCN.**

6. RECOMMENDATIONS

To avoid premature, preventable, or treatable mortalities of people experiencing multiple and complex needs (MCN) we would hope to see all the following recommendations taken up in time, with a staged timetable to be agreed amongst the key stakeholders for immediate, medium, and more long-term changes:

IMMEDIATE:

- Setting up a local review process to monitor deaths of people experiencing MCN and assess progress in improving health inequalities within the local community.
- Hospitals to record details of the client's support network, including community-based professionals trusted by the patient as part of discharge planning.
- People with MCN are triaged to the right support through one pathway, under a streamlined system from admission through to hospital discharge into community health services.

MEDIUM-TERM:

- Providing mandatory training for all healthcare professionals and anyone working in a healthcare setting; including mental health first aid, trauma-informed approaches and alcohol and substance misuse.
- More flexible primary and secondary care, using more drop-in services, outreach services and arranging appointments in more flexible ways.

LONG-TERM:

- Frailty health scores to be used as a screening tool for people with MCN to proactively improve physical health needs and provide rapid access to treatment.
- Women only spaces in healthcare settings and specialised healthcare services for women with MCN.

ACKNOWLEDGEMENTS

We would like to acknowledge and thank everyone who contributed to this report by discussing ideas and giving feedback.

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For further information about Fulfilling Lives South East Partnership, please visit https://www.bht.org.uk/fulfilling-lives

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