THE DEATH OF MR F

SERIOUS CASE REVIEW REPORT

APRIL 2014

1. BACKGROUND AND CONTEXT

1.1 This document provides a report of the findings of the Serious Case Review established to consider the professional interventions in respect of Mr F.

1.2 Mr F who was aged 84 and lived alone became a missing person on 18 December 2012 after leaving Huddersfield Bus Station at 11:15 pm. His body was found on 24 February 2013. Mr F had suffered with multiple medical conditions including vascular dementia. He had been supported by his daughters who he visited daily and had been in receipt of homecare services since November 2011.

Serious Case Reviews (SCRs)

1.3 SCRs are carried out when:

- a vulnerable adult (now referred to as an adult at risk) dies or has sustained a potentially life-threatening injury and abuse or neglect is known or suspected to be a causal factor; and
- where practice gives rise to concerns about how agencies have worked together when the death or injury occurred.

1.4 The purpose of conducting an SCR is neither to investigate nor apportion blame. It is to:

- establish whether there are lessons to be learnt from the circumstances of the case about the way in which local professionals and agencies work together to safeguard adults at risk;
- review the effectiveness of procedures of both multi-agency and individual organisations;
- inform and improve local inter-agency practice;
- improve practice by acting on learning and developing best practice; and
- prepare or commission an overview which brings together and analyses the findings of the various reports from agencies in order to make recommendations for future actions.

1.5 Each agency that has had some direct involvement with the adult at risk is required to undertake an Individual Management Review (IMR) to look openly and critically at individual and organisational practice as it related to their involvement with the adult at risk. However the managers who conduct IMRs are not directly involved with the services provided for the adult at risk, nor are they the immediate line managers of the practitioners involved.

Decision to undertake an SCR in the Case of Mr F

1.6 The decision to undertake an SCR in the case of Mr F was taken on 27 March 2013 by the Kirklees Serious Case Review Sub-group which is a sub-group of the Kirklees Safeguarding Adults Board (KSAB) and includes representation from the Calderdale and Huddersfield NHS Foundation Trust, West Yorkshire Police, and Kirklees Council. The sub-group is responsible for making recommendations to the Chair of the KSAB about commencing SCRs, making arrangements for conducting an SCR and monitoring the effective implementation of recommendations and related action plans arising from the review process. The Chair of the KSAB ratified this decision on 3 April 2013 and consultation with Mr F's family was undertaken on 9 April 2013.

The Serious Case Review Panel

1.7 The Serious Case Review Sub-group established a Serious Case Review Panel comprising independent senior professionals from agencies in Kirklees to undertake the SCR. None of these professionals had any direct involvement in providing services for Mr F.

1.8 The Serious Case Review Panel had representatives from the:

- Calderdale and Huddersfield NHS Trust
- Social Care and Well-being for Adults
- Kirklees Safeguarding Adults Partnership Team (Advisory)
- South West Yorkshire Partnership Health Trust
- Kirklees Council Streetscene and Housing
- Kirklees Council Legal Services (Advisory)
- West Yorkshire Police
- Greater Huddersfield Clinical Commissioning Group

The views of NHS England, a new organisation, were also represented at the Panel.

1.9 The legal advisor to the KSAB attended meetings of the Panel and provided legal advice as appropriate.

Conduct of the Serious Case Review

1.10 The period covered by the SCR was 1 March 2011 to 24 February 2013. Mr F's family were visited on 4 September 2013 and the Safeguarding Partnership Manager maintained contact with them throughout the progress of the SCR.

1.11 The conduct of the SCR was shaped by two questions:

i. were there lessons to be learned about the way in which professionals worked in partnership to support Mr F and his family and to safeguard Mr F?; and

ii. following the notification of Mr F as a missing person, did partner agencies work effectively together to gather and share information?

1.12 The SCR was asked to take into account:

- Were services easily accessible?
- Were services co-ordinated?
- What understanding was demonstrated of each other's roles and skills?
- What evidence was there of communication and information sharing?
- The timeliness of interventions for Mr F and his family.

1.13 The SCR was also asked to make recommendations as to how each agency would share the learning.

Individual Management Reviews (IMRs)

1.14 IMRs were requested and received from:

- Kirklees Social Care and Wellbeing for Adults
- Kirklees Safeguarding Adults Board
- South West Yorkshire Mental Partnership Mental Health Trust (SWYPHT)
- West Yorkshire Police
- NHS England/Greater Huddersfield Clinical Commissioning Group

1.15 Information was also requested from other agencies / services that had been involved in a relatively marginal degree, ie:

- Calderdale and Huddersfield NHS Foundation Trust
- Kirklees Council Streetscene and Housing

1.16 An NHS health overview IMR with regard to the involvement of all health care practitioners and commissioning services was not requested for this SCR.

1.17 West Yorkshire Metro provided information about the last sightings of Mr F and Firstbus and West Yorkshire Metro provided information on the training of staff concerning vulnerable passengers.

1.18 Mr F's family provided verbal and written information and opinion.

Recommendations from the Serious Case Review

Support and Information

1.19 **RECOMMENDATION 1**

At the point of contact or access, agencies should ensure that they offer a full range of advice and information regardless of eligibility for services. A broad range of support should be offered where appropriate. This should include advice about appropriate assistive technology, such as, GPS.

1.20 **RECOMMENDATION 2**

That clear, realistic and timely information and advice is given around meeting a person's housing need.

Eligibility, Referral and Care Pathways

1.21 **RECOMMENDATION 3**

That agencies adhere to an agreed care pathway across Health and Social Care for anyone with dementia. This must be explicit and straightforward.

1.22 **RECOMENDATION 4**

That there are mechanisms in place to enable re-connection with services for people with deteriorating conditions such as dementia, which are straightforward, clear and timely.

1.23 **RECOMMENDATION 5**

That health providers work with the Greater Huddersfield CCG to ensure that there is an explicit care pathway for the management and care of people with dementia in general hospitals, including in emergency care, through to safe hospital discharge.

Assessment and Care Planning

1.24 **RECOMMENDATION 6**

Where the Care Programme Approach is used everyone is clear about the lead professional, their responsibility to co-ordinate a multi-agency response and ensure this is effectively communicated to agencies, professionals, the person and their family.

Family Carers

1.25 **RECOMMENDATION 7**

That agencies have mechanisms in place to ensure that carers and family are evidently and sensitively included by all professionals as partners in providing care and support.

1.26 **RECOMMENDATION 8**

Families must have an easy access to an identified lead professional.

Training

1.27 **RECOMMENDATION 9**

That the SCR features in refresher training for Calderdale and Huddersfield NHS Trust, Greater Huddersfield Clinical Commissioning Group, Kirklees Council, South West Yorkshire Partnership NHS Foundation Trust, Kirklees Healthwatch, Carers Emergency Support Services and West Yorkshire Police and in the Safeguarding Adults Board's training programme. Multi-agency workforce training is critical if professionals are to understand the impact of dementia and its implications for people's lives.

Dementia Strategy

1.28 **RECOMMENDATION 10**

That the cross sector leadership body in Kirklees revisit their Dementia Strategy and its implementation to ensure that (i) service provision aligns with strategic objectives and (ii) people living with dementia and their families experience an integrated service, most particularly when they have diagnosed physical co-morbidities.

1.29 **RECOMMENDATION 11**

That Kirklees undertakes to become a dementia-friendly locality.

2. SUMMARY OF KEY INFORMATION AND THE CIRCUMSTANCES THAT LED TO THE REVIEW

2.1 It is clear from the information brought together during the review that Mr F was a well-loved father, grandfather and great-grandfather. He had lived in the same home for most of his life. After his wife's death he had looked after himself and his home capably. However, as his dementia progressed his self-care began to deteriorate.

2.2 Mr F maintained contact with his family, in particular his two daughters and had established a routine of going to one of their homes for his evening meal. His daughters wanted him to move closer to them but he remained living in his own home until his death.

2.3 **In March 2011**, Mr F's family became concerned by his changing behaviour, which they considered to be suggestive of the onset of dementia. Mr F and his daughter visited his GP who began the process for a dementia diagnosis. In May 2011 confirmation was received that Mr F had vascular dementia. As a result Mr F was no longer able to drive a car and had, therefore, to catch up to 2 buses each way to visit his daughters. Mr F's GP referred him for an occupational therapy assessment, speech and language therapy and psychology (no response from the psychology service was noted).

2.4 **Between March and December 2011** Mr F was assessed by a range professionals / agencies which resulted in actions by:

a) **Adult Social Care** (Kirklees Council)

In March 2011 Mr F was initially assessed by Gateway to care[1] as not meeting the Fair Access to Care Services (FACS) criteria[2]. However, as his dementia progressed, in July 2011 he was referred again and following a Social Worker assessment in October 2011 Mr F began receiving homecare support in November 2011. Mr F's family were not happy with the homecare service, citing missed calls, Mr F not being supported to follow his daily routine, ie shopping, and did not want to change his clothes. Mr F's care package was reviewed by telephone. During December, following review of the care package, the case was closed to a named worker and placed on the programme for reviews. Mr F was receiving breakfast calls, to help him dress, have breakfast, leave a sandwich for lunch and to give medication prompts.

In March 2011 Mr F was referred by Gateway to care to **the Citizen's Advice Bureau** (charity) for assistance with debt management and stopping unwanted calls from door to door and telephone sales people. Action included recovery of some monies and re-direction of mail to his family. In December 2011 Mr F's daughter rang the Social Worker to express concern that an unsolicited caller had persuaded Mr F to order something very expensive that he did not need. Although the order had been cancelled Mr F's family remained concerned. A discussion about Power of Attorney was noted. However the family did not wish to pursue this option.

[1] The Council's initial point of contact for referrals to adult social care

[2] A national eligibility framework in England, FAC is a means of prioritising eligibility for care and support fairly, transparently and consistently (SCIE, 2013)

b) **Community Rehabilitation Team** (Calderdale and Huddersfield Foundation Trust (CHFT))

Mr F was assessed in July 2011. The OT in this Team established that Mr F needed help and support with activities of daily living (*he was described as having become vulnerable and at risk in his own home, unable to take his medication for diabetes and not eating proper meals)* and made onward referrals to the OT in the Community Mental Health Team and to Adult Social Care.

c) **Community Mental Health Team** (South West Yorkshire Partnership Health Trust (SWYPHT)

In August 2011 an OT undertook a risk assessment; made home visits and onward referrals to the Alzheimer's Society, Benefits Advice Service (no response from either service was noted). A CPN wrote to Kirklees Housing Options and Support in support of his application for rehousing (which had been made in November 2010). Towards the end of November 2011, the CPN informed the Social Worker that the case was closed. The OT also informed the GP that the case was closed.

d) **Speech and Language Therapy** (CHFT/SWYPHT)

Towards the end of September 2011, it was established that the GP referral (May 2011) had not been received (possibly as a consequence of the team being restructured into acute and community teams). In October Mr F was informed that there was an 8 week wait for therapy. In December 2011 Mr F was assessed by a speech and language therapist who gave advice about diet, and referred to a dietician for weight loss. This was because of his problem with swallowing and spitting out food that was felt to be behavioural and related to his dementia.

e) **Housing Options and Support Service** (Kirklees Council)**:**

Mr F had initially made an application for rehousing in November 2010 which had progressed through referral to the Medical Advisory Team to Mr F becoming a member of the Choose and Move Scheme, that entailed bidding for one bedroomed properties. During October 2011, because she wanted Mr F to live in a particular area, Mr F's daughter assumed responsibility for the bidding process. Housing Options and Support advised Mr F's daughter to consider widening the area of choice. In November 2011 Mr F was informed that he was low priority.

f) **Memory Service**[3] (SWYPHT);

An OT visit in November 2011 noted Mr F's swallowing problem and spitting out food. His explanation being that he did not feel like eating. Because of his diagnosis of vascular dementia the Memory Service was unable to provide a service.

2.5 **Between March 2012 and December 2012**:

a) In **March 2012** Mr F's daughter visited his GP which resulted in a request to Adult Social Care for a reassessment because of his daughter's concerns that her father was deteriorating and had become more confused and disorientated.

[3] Kirklees Memory Service provides assessment, diagnosis and consideration of possible treatment options for those people diagnosed with Alzheimer's.

b) During **April 2012** Mr F collapsed whilst out with group of friends and was taken to A&E at Huddersfield Royal Infirmary. Mr F was to be admitted for assessment but he left the hospital apparently with a cannula still in place. Mr F's daughter, who had gone to her father's house to get some of his things to take them to the hospital, rang the hospital (who had been looking for him) to let staff know that he had arrived home. A District Nurse arrived to remove Mr F's cannula but he said had already removed it himself before he left hospital.

c) In late **April 2012** Mr F's daughter, who was concerned about his continuing weight loss, made a second referral to Adult Social Care for a reassessment.

d) In mid **May 2012** Mr F was reallocated a Social Worker, referred to the Memory Service by his GP and was allocated to SWYPHT's Older People's CMHT.

e) Towards the end of **May 2012** Mr F's daughter requested residential respite care to enable a family holiday in August. An OT assessed for a bath seat which was delivered in June. Mr F was unsuccessful in a bid for rehousing to a property near to his family and further bids were placed for properties in an alternative location.

f) In **June 2012:**

- Mr F's case was closed to a named worker.
- His family ceased to pursue rehousing.
- A CPN from the CMHT informed the Social Worker that Mr F did not have the mental capacity to make decisions. The CPN visited Mr F's home to undertake a health and social care assessment. His daughters were present but Mr F had left for his daughter's home and was with his grandchildren. Mr F's daughters explained that their concern was increasing and one felt she was not getting a break, ie their father was often not at home when Home Care Workers called at breakfast time; he was refusing to let them help him wash and get changed and he was smelling, not eating and losing weight. Also spending long periods of time in town in a bank, unable to say who he was. Mr F had been stuck in his bath on two occasions, once for three hours. He had turned up at his son's home unexpectedly and he believed that people were watching him. Mr F no longer recognised his own reflection and there were instances of disinhibition. He was described as having no insight into his needs or his failing capabilities.
- An assessment undertaken by the CMHT noted that there were incidents recorded of Mr F getting on the wrong bus. It was noted that his mental health was too impaired to manage in a move to suitable housing near daughter. Mr F had been assessed for speech and language therapy in the past regarding swallowing difficulties but no problems were detected. His daughter explored Power of Attorney but was told it would need to go to the Court of Protection. The assessment acknowledged the worry and stress for his daughters and in the light of Mr F's difficulties in maintaining health and hygiene and safety, an increase in the care package was actioned. This included 10 hours of Direct Payments per week. The Social Worker acknowledged that Mr F could not make capacitated decisions and that he was at risk when going out. The Social Worker undertook to speak to the Medical Re-housing Officer to see if the process for rehousing could be speeded up.

g) **During July 2012**:

- A CPN visited Mr F - who thought it was Sunday and that he was going to church. The CPN made signs for the door to help orientate Mr F to the day and Mr F's care plan was updated.
- Adult Social Care closed Mr F's case to a named worker but undertook to review his circumstances in twelve months. A Local Authority residential respite place had been booked for Mr F to coincide with his daughter's holiday in August.
- Mr F's daughter contacted the CPN because of her continuing concern that Mr F visited her home sometimes three times a day since he was forgetting that he had already been and that he was at risk of inadequate nutrition because he was throwing away sandwiches made by the Home Care Service. A few days later the CPN visited Mr F who was about to go his daughter's home. The CPN assisted Mr F to turn off the gas and made a sign for his door to orientate Mr F.

h) **At the beginning of August 2012**:

- Mr F spent 10 days in residential respite service where he was visited by the CPN and a Healthcare Assistant from the CMHT. It was noted that he was enjoying his stay, enjoying food and sleeping well. Staff reported that he had settled in well and had not tried to leave the building, the possibility of which had troubled his family when they had arranged Mr F's respite stay.
- When the CPN visited Mr F 18 days after his return from the respite service, he had no recollection of being in respite. The CPN noted that the home care book (which recorded the activities of the homecare personnel) appeared in order. Mr F had a further brief respite stay at the end of August.

i) **At the beginning of September 2012:**

- Mr F's GP made a fast track referral for suspected urological cancer.
- The CPN visited Mr F and noted that although home care services were visiting daily Mr F was forgetting to eat his sandwiches. His daughter confirmed that Mr F's memory and self-care had deteriorated further. She was anticipating that he would have to go into 24 hour care at some stage. She was told that Mr F was to be discharged from the CMHT and was advised that if she felt that Mr F was deteriorating further, she should ask his GP to refer him back to the service.

j) **At the beginning of October 2012** it was confirmed that Mr F had prostate cancer. Treatment began and Mr F had a further brief respite stay at the end of October.

k) **During mid-November 2012** Mr F's daughter contacted Adult Social Care because she was struggling to continue care-giving. She described the situation as intolerable. Mr F was visiting daily and was incontinent and smelling, irrespective of the home care support. She was advised that there was a backlog of work and that Mr F was awaiting allocation, to contact District Nurses for a continence assessment and to consider assistive technology such as a GPS watch to track his movements.

l) **On 8 December 2012**, Mr F was taken by ambulance to A&E at Huddersfield Royal Infirmary. Staff had found him in bushes at the back of MacDonald's. This was the first known occasion that Mr F had wandered from a familiar route. Mr F reported that he had slipped in a puddle and fallen and was unable to get up. He was cold and wet through. He had been incontinent of urine and faeces. Mr F was admitted to the hospital because he had been assessed as being unsafe to go home without the cause being investigated.

m) **On 9 December 2012**, Mr F was assessed medically fit to be discharged and was referred to the Council's Hospital Avoidance Team[4]. A decision to discharge Mr F home was made on the basis that he had no injury and he had a support package, which was to be enhanced to four visits a day including lunchtime and evening calls. During Mr F's stay in hospital it had been noted that he was wandering around the ward area, needed guidance, was confused to time and place and an intermittent sleep pattern was recorded. Mr F was taken home by his daughter during the afternoon. The Hospital Avoidance Team emailed Adult Social Care suggesting that an urgent assessment was needed for Mr F.

n) **On 19 December 2012**, the home care provider alerted the family that Mr F was missing from home and that he had probably been missing since the evening of 18 December. Mr F's daughter contacted West Yorkshire Police at 1.15 pm. Mr F was logged as a missing person at high risk and a search commenced straightaway. Just over an hour after being contacted by Mr F's family, the police received information from a member of the public who believed that Mr F had been on a bus heading towards Huddersfield wearing pyjamas under his coat. The witness had asked the bus driver to keep an eye on the man as she was concerned. Officers went to the bus station and requested CCTV footage. The security staff recalled seeing a man fitting Mr F's description. Firstbus requested all drivers to keep a look out. CCTV footage at the Bus Station showed Mr F leaving the bus station via the front doors at 23.15 hours. He had been walking around the bus station for 55 minutes before leaving. He had declined the offer of assistance made by a member of the security staff. By 5:30 pm West Yorkshire Police had placed Mr F's photograph on twitter, his details had been circulated on the police national computer and his photograph was being shown to people in shops and locations familiar to Mr F. By the early evening they had established that Mr F's home carers had visited him at 6:50 pm on 18 December. He had been fed and he was changed into his pyjamas.

o) **On 20 December 2012** the police informed Kirklees Council that Mr F was missing. The Council passed on Mr F's details to other directorates, to care homes and other services. The extensive search operation put in place by West Yorkshire Police continued.

p) West Yorkshire Police established regular contract with the media and the family were provided with the first of many updates.

[4] This Team works with the front end of the acute sector (A&E, MAU, etc.) to facilitate patients who no longer need medical intervention in returning home or to an alternative setting rather than an acute bed.

q) Later scrutiny of Firstbus CCTV footage showed Mr F getting on a Bradley bus into Huddersfield at 20.19 hours (on 18 December); alighting at 20.39 and then getting back onto the same bus at 20.52 hours. He returned to the bus station at 21.17 and got onto the Marsden bus. He travelled to Marsden before returning at 22.36 hours when he was approached by the driver who escorted him off the bus.

2.6 **On 24 February 2013** Mr F's body was found. The cause of death was hypothermia. At the Inquest of 24 July 2013, the Coroner determined that Mr F's medical condition had disoriented him. A verdict of accidental death was recorded.

3. KEY FINDINGS AND RECOMMENDATIONS

Support and information

Finding

Mr F's family sought help in what they sensed were the early stages of him becoming forgetful and requiring prompts and assistance in his daily routines. Their initial contact with Kirklees Adult Social Care resulted in the decision that Mr F did not meet the Fair Access to Care Services criteria. This was although he had a complex combination of health problems and, in May 2011, had received a diagnosis of vascular dementia. An urgent referral from an Occupational Therapist during July 2011 (at which time Mr F was described as having *become vulnerable and at risk in his own home, unable to take his medication for diabetes and not eating proper meals)* did not result in a Community Care Assessment until October 2011.

Finding

It is regrettable that it was only in the month before Mr F went missing that a GPS watch was considered for him. The earlier such technology is introduced, the greater the likelihood that it will become familiar and tolerated. Given the concern that Mr F had become even more disoriented but was accustomed to going out every day, the case for proactively promoting such technology and securing it on his behalf is compelling.

RECOMMENDATION 1

At the point of contact or access, agencies should ensure that they offer a full range of advice and information regardless of eligibility for services. A broad range of support should be offered where appropriate. This should include advice about appropriate assistive technology such as GPS.

Finding

Kirklees Housing Options and Support (now the Housing Solutions Service) awarded Mr F's housing application as Band C, ie a low priority housing need. This was in line with the Housing Allocations Policy which reflected his need to move. The relevance of Mr F's home ownership appears not to have been considered by Adult Social Care, or any of the professionals who sought to alert Housing Options and Support to Mr F's deteriorating circumstances. The family should have been advised of options other than bidding for properties in a banding system, eg equity release or seeking a rented property near to his family and renting out his own house. While such courses of action would have carried risks, it would have spared Mr F's family the frustration and disappointment concerning housing which they were led to believe may become available. Professionals in the Housing Solutions Service and Adult Social Care should ensure that informed and appropriate advice is given to colleagues across sectors as well as to individuals and their families.

RECOMMENDATION 2

That clear, realistic and timely information and advice is given around meeting a person's housing need.

Eligibility criteria, referral routes and care pathways

Finding

Without question, the services sought by Mr F's family and made available to him bore little resemblance to the aspirations of the Kirklees Dementia Strategy. As an IMR author explained: Some services are delivered by the mental health trust (SWYPHT) and others sit within other health providers which clearly causes confusion for staff – let alone carers.

Finding

Mr F's GP referred him to the SWYPHT's Memory Service during March 2011 and again during May 2012. His GP was advised that there was a 12 week wait for the Memory Service at the beginning of 2011. Once Mr F was seen, he was discharged after the initial visit due to the pathology of his diagnosed condition i.e. vascular dementia…there was nothing more they could offer[5] i.e. the referral merely confirmed the diagnosis, leaving the longer term implications of his support needs to be addressed by the CMHT. Kirklees' Gateway to Care advised Mr F's GP to refer him to the Memory Service on a second occasion. It is unlikely that such a response is recommended in the training of Information and Advice Officers.

Finding

Despite the objectives and action planning of the Kirklees Dementia Strategy, Mr F's diagnosis of dementia did not give him access to a clear pathway for information, advice and support planning. Mr F was discharged from the Memory Service after an outpatient follow-up appointment because he was ineligible for medication and was referred to the CMHT. An OT visited Mr F several times, liaised with Kirklees Adult Social Care, housing and the Speech and Language Therapy service and referred him to the Alzheimer's Society for support. However, there is no evidence that the Alzheimer's Society ever responded to the referral, or of Mr F and his family receiving the directly appropriate treatment, information, care and support after diagnosis as defined in the National Dementia Strategy (2009). In SWYPHT's case it appears that the memory service was a diagnostic service only and that the CMHT were supposed to provide these additional essential elements of a high quality post-diagnostic service. Mr F's family experienced none of this and described the CMHT's input as '*pointless'.*

Finding

There seems little value in a diagnostic service which provides no information, care and support after a diagnosis of vascular dementia, particularly since the current evidence base suggests that up to 50% of dementia cases may have a vascular component (DH, 2009, p27). The case closure by the memory service resulted in an inappropriate referral to the Community Rehabilitation Team which, after visiting Mr F, referred him to the CMHT occupational therapist, by which time two months had elapsed. At the very least, it would have been helpful for the family to have some understanding of the implications of a diagnosis of vascular dementia with

[5] Greater Huddersfield CCG IMR

frontal lobe involvement, particularly since this accounted for some of Mr F's troubling behaviour. The decision by the occupational therapist in the CMHT to close Mr F's case coincided exactly with the social worker's decision to close the case *as home care going well*[6]*.* This decision was in spite of the occupational therapist's observations on the last home visit that he had *spat out* his breakfast.

Finding

Mr F had multiple long term conditions and yet it appears that the course of his dementia was not deemed to merit any social work oversight. No-one was taking a proactive approach to his support or asking about the possibility of Mr F potentially requiring NHS Continuing Health Care funding, for example. Furthermore, no-one considered the possibility of Mr F potentially requiring services following his hospital admissions of April and December 2012.

Finding

The concerns which prompted Mr F's family to seek assistance during March 2011 continued to exist in December 2011, by which time community psychiatric nursing, occupational therapy and social care had all closed his case. Two matters of particular relevance to Mr F's family were:

- the fact of Mr F's financial exploitation and his continuing vulnerability to being further exploited
- Mr F's home location – he was two bus rides away from his family who wanted local sheltered housing for Mr F.

Later, as Mr F's illness progressed, two further concerns emerged, i.e.

- his inability to cooperate with a home care package because of his significant cognitive impairment and memory loss, and
- the unresponsiveness of services to the family's attempts to secure additional help.

Finding

Obtaining needed support services was a continuous problem for Mr F. There were times when Mr F's daughters felt under extreme pressure but without any non-family help e.g. when their father became doubly incontinent: "*It felt like I was having a nervous breakdown but there was no help. I was pleading on the phone – but there was nothing."*

Finding

During March 2012, the GP asked adult social care to undertake a re-assessment of Mr F, following which the intake team contacted the daughter who confirmed her father's deterioration. A month later, during April 2012, Mr F was taken to A&E by ambulance because he had collapsed. The clinical plan was for him to be admitted to the Clinical Decision Unit for a social assessment following discussion with his daughter. However, he left the A&E department before the transfer could take place. His daughter rang the hospital to inform staff that her father had arrived home and was safe and the Senior Medical Officer discharged him without any further referral for a social care assessment or any follow up, other than the District Nurses to remove his cannula.

[6] SWYPHT IMR

Finding

The expectation that Mr F's family would follow up such a referral with social services themselves was inappropriate, not least because following the GP's referral for a re-assessment, one of his daughter's had, the previous month, informed social services of this. Nonetheless, his daughter rang social services a few days later to request help for her father with his personal care. A social worker was finally allocated in May, some two months after the GP's request. However, a person to person assessment was not completed by the social worker until the middle of June. The discharge summaries from the hospital sent to Mr F's GP were very brief. Similarly, the Hospital Avoidance Team's note of December 2012 arising from what was to be Mr F's last hospital admission is barely credible i.e. *what have we done? Increased home care 3 x and have put urgent assessment in; Advice given? To stay at home as you are now having 4 x day home care and the weather is now too cold to go out; If you have further difficulties? Please ring Gateway to Care.* This was drafted only hours after Mr F had been put onto the social pathway for adults who are not safe for discharge. Such responses fall short of the objective in the National Dementia Strategy to improve the quality of care for people with dementia in general hospitals. Within the acute sector, the identification of a senior clinician to take the lead for quality improvement in dementia care in the hospitals may advance this work.

Finding

Events leading up to Mr F's disappearance do not demonstrate an understanding of how the dementia journey is experienced by people with dementia and family carers or the significance of (i) long term planning and (ii) contingency planning. It is possible that the introduction of the Health and Social Care Act 2012, and the creation of new bodies and emergent services have displaced the operational and strategic collaboration on which the Dementia Strategy was based. Coherent and well thought out service responses become extremely difficult when procedures are unclear or unknown or where information - which may be partial (or is inaccessible to some) - is passed from professional to professional, in different locations, over many weeks. Individuals with complex needs, diminishing mental capacity and progressive conditions, and their families, require the consistent attention of professionals in a multi-disciplinary forum.

Finding

Referral routes and care pathways must include mechanisms for regular and spontaneous feedback from care providers who have day to day contact with people with dementia, and from family carers, so that commissioners and care managers can be alerted to evidence that more or different assistance is required. This may usefully involve feedback from dementia champions, for example. The passage of the Care Act 2014 places emphasis on the role of the assessment process in supporting people to identify their needs, and provides for joint assessments between local authorities and the NHS, may address the need to join up separate assessment processes.

RECOMMENDATION 3

That agencies adhere to an agreed care pathway across Health and Social Care for anyone with dementia. This must be explicit and straightforward.

RECOMMENDATION 5

That health providers work with the Greater Huddersfield CCG to ensure that there is an explicit care pathway for the management and care of people with dementia in general hospitals, including emergency care, through to safe hospital discharge.

Assessment and care planning

Finding

The absence of coordinated and diligent management oversight of Mr F's changing circumstances meant that there was no single professional assisting him to access and co-ordinate the services he required over time; to advocate with and on his behalf; to navigate complex care systems; to provide advice to his family; or to seek regular feedback about Mr F's condition, the adequacy of his care package and his experience of service provision to relevant professionals. Although there was no evidence of either care management or of a care programme approach,[7] Mr F was theoretically subject to the latter.[8]

Finding

On two occasions requests for Adult Social Care Assessments took over two months to begin. The urgent assessment requested by the Hospital Avoidance Team following Mr F's final hospital stay resulted in no action.

Finding

Mr F's family sought the assistance of services and wanted to have some say over how these would be delivered. In general, the nature of the support they received was experienced as limited. They explained that "some of the visits from the CMHT seemed pointless. They were a waste of time because they didn't benefit our dad and nothing changed as a result." There were urgent referrals and yet these were not acted on – most critically a referral made nine days before he went missing.

Finding

Even though there was very clear information from Mr F's family and CPNs about Mr F's urgent support needs resulting from his steady deterioration - after which the CPN closed the case – the only response was to increase a care package which was not working and to arrange respite care when the family was away. At no point was feedback concerning Mr F's residential respite experience brought to bear on decision-making concerning his day to day support. Yet when he was in a residential service he ate the meals provided, co-operated in taking his medication and did not seek to leave the home. Arguably this was the safest and most stable period in Mr F's post-diagnosis life.

Finding

There is no evidence that Kirklees Council professionals who were involved in Mr F's case understood the urgency of his dire circumstances and/or the increasing stress this placed on his daughters. Their delay in allocating his case at the outset was wrong and the decision making to close his case before his respite stay was flawed. Mr F's daughters recalled: *It would help greatly if one social worker dealt*

[7] NHS Choices describes this as a particular way of assessing, planning and reviewing a person's mental health care needs http://www.nhs.uk/CarersDirect/guide/mental-health/Pages/care-programme-approach.aspx (accessed on 8 January 2014)

[8] *Every person who is assessed as needing CMHT input is placed on CPA unless they are assessed as needing out-patient input only* - SWYPHT

with him throughout his illness instead of being passed from pillar to post, this would have given the family someone to contact instead of ringing a reception number for Gateway to Care and getting a receptionist telling them the service was very busy and he would be put on a waiting list for assessment! There is no cure for vascular dementia yet each time he had an assessment of any kind he was discharged or signed off which made it very difficult (nigh-on impossible) to get help as his condition deteriorated.

Finding

Mr F's family were concerned that there was insufficient information in his care plan because in their view the professionals' assessments were not credible. Mr F went to extraordinary lengths to present well when he had some sense that he was being assessed. His social skills were well preserved.

Finding

There is little doubt that the family's fruitless efforts were compounded by personal stress. The purpose and eligibility criteria of services, their want of coordination, the delays in securing assistance and the inefficient frequency with which Mr F's case was closed by professionals were all bewildering barriers for his family to negotiate. It appeared to them that there was neither awareness nor understanding among professionals that Mr F's condition was deteriorating, that it would continue to do so and that this was predictable.

Finding

Mr F's situation can be seen as a series of crises requiring every professional in each organisation to be attentive to the concern and distress of caregivers and to proactively engage with partner agencies rather than referring individuals on and closing their cases. The goal would be to underline the possible, if not probable consequences, of poorly designed and poorly understood referral routes into the minds of professionals through training, so that (i) the pressing need to secure feedback about how services are experienced is understood and (ii) attention is clearly drawn to proportionate assessment and to events that signal that a different approach is urgently required.

RECOMMENDATION 4

That there are mechanisms in place to enable re-connection with services for people with deteriorating conditions such as dementia, which are straightforward, clear and timely.

Co-ordination across agencies and professions

Finding

Mr F went to see the GP on 10 occasions between March 2011 and February 2013. Primary care diagnosed and was managing Mr F's heart problem, his diabetes and ultimately his prostate cancer. On each occasion he was accompanied by his daughter. Thus primary care was attuned to the care-giving experience of the family and, over time, understood the diminishing capacity of Mr F's family to help him. For example, with reference to Mr F's home circumstances, the GP wrote a letter supporting Mr F's transfer to be near to his family to Kirklees Housing Options and Support. However, when Mr F's case was closed by the SWYPHT, he was referred back to his GP.

Finding

Mr F's physical health status was complex. His dementia meant that he had difficulty complying with medication and diet which in turn compromised his ability to manage on a day to day basis. This makes the decision to discharge him from the CMHT without the assurance of a robust care package flawed. Mr F had been receiving a home care package for approximately five weeks. There was no consultation with the family and there is no evidence that the requested support from the Alzheimer's Society had materialised. The correspondence to the GP about Mr F's discharge from the CMHT during December 2011 is unequivocal, leaving the GP uncertain as to what should happen next.

Finding

Although there can be more than one Single Point of Access in a locality, this only makes sense if all referrals are considered and routed in the same way. However, this does not appear to be the case in Kirklees where there are two Single Points of Access – the Council's (the information poster for which includes the NHS logo) and SWYPHT. They appear to operate independently of each other and create confusion for professionals and the public alike.

Finding

Events in Mr F's life, and that of his family, illustrate the limited reach of fragmented services which lack the coherence and direction espoused by Kirklees' dementia strategy. The necessary leadership, structures, governance and support are not in place. Such policy implementation gaps and slippage have longer term consequences e.g. Kirklees' dementia strategy makes no reference to the existence of two Single Points of Access. It would appear that this ad hoc, inefficient duplication fails to engage with the distinctive and varied needs of people with dementia, their families and professionals. Further, it may lead to distrust of services' intentions and competence.

Finding

When it was published, the Kirklees Dementia Strategy made its principal objectives clear and in an annex it laid out an action plan with identified milestone dates. However, the action plan was underdeveloped since it was broadly activity-based and did not specify the outcomes for people with dementia and their relatives. An outcomes focus is critical to acknowledging who and what is important. For example, assumptions were made about the capacity of Mr F's family to continue to care for Mr F and to negotiate services for him. The hospital did not see itself as having responsibility for referring Mr F for additional help. It relied on his daughters to do so. It did this without establishing beforehand (i) the family's experience of attempting to secure adult social care services or (ii) that they were enabled to care for Mr F without detriment to their own health and well-being.

Finding

Mr F was disadvantaged by free-standing information systems which did not connect – not even within the hospital; e.g. A&E could not access Hospital Avoidance Team information. This places a greater onus on individual practitioners to be proactive in sharing information and, theoretically, this should be possible in an age of instant messaging and communications. However, Mr F's experience was one of waiting for appointments, waiting for his case to be allocated, waiting for his case to be re-allocated and waiting for referrals to the appropriate service. Faxes

and correspondence confirming case closure, for example, were out of synch with Mr F's deteriorating circumstances.

Finding

Although professionals did not intend that Mr F and his family should experience unresponsive and confusing services in which staff were very busy, that is how they were experienced. A determined and sustained service with integrated governance is required if Kirklees citizens with dementia and their families are to experience a far-sighted, compassionate and life enhancing service.

RECOMMENDATION 6

Where the Care Programme Approach is used everyone is clear about the lead professional, their responsibility to co-ordinate a multi-agency response and ensure this is effectively communicated to agencies, professionals, the person and their family.

Family carers

Finding

Mr F's daughters stressed their desire to work with competent professionals who understood the course of dementia and its impact. Their experience rendered them uncertain that they could continue in their caregiving roles. Although the carers' legislation was intended to make a decisive change in policy and practice, there was little acknowledgement that Mr F's daughters began as novices themselves in accommodating their father's memory loss and identifying ways of helping to orient him. Their needs changed over time and yet they were unaware that they had even been offered carers' assessments. Mr F's daughters learned the hard way that the majority of the professionals they met did not have specialist knowledge about vascular dementia. It is regrettable that professionals did not validate the growing expertise of Mr F's own family.

Finding

Mr F's daughters had valuable knowledge about their father and had sought to contribute to his assessments over the course of his decline. They became attuned to fluctuations in his mood and behaviour and yet they had no sense that they were regarded as credible partners by any professionals other than his GP. They believe that their accounts of their father's mental and physical health status were set aside in favour of those of untrained and/ or insufficiently experienced professionals, e.g. they recalled that several staff made such observations to them as: *We've had a really good talk to him and we've told him that he mustn't leave the house*. The family knew that Mr F would not have been able to remember that he had even had visitors, let alone their instructions. It appears that these professionals had no understanding of the implications of dementia in general and Mr F's dementia in particular. To appreciate the full extent of Mr F's cognitive problems required spending time with him and learning from his family. As one daughter observed, *after five minutes of talking to him you would know that something was not quite right.*

Finding

The family remain grateful that the police brought management oversight and sustained priority to the task of finding Mr F.

RECOMMENDATION 7

That agencies have mechanisms in place to ensure that carers and family are evidently and sensitively included by all professionals as partners in providing care and support.

RECOMMENDATION 8

Families must have an easy access to an identified lead professional.

Training

Finding

Mr F was an adult at risk. His cognitive impairment and memory loss rendered him susceptible to exploitation, particularly financially, and in March 2011 his family became aware that he had spent considerable sums (£9,500 in total) on a bed, a chair and vitamin tablets that he did not need. He was referred by the GP to the council's Gateway to Care for support and financial advice, but because he did not meet the FACs eligibility criteria he was referred on to CAB. The Trading Standards service managed to recover £500 for some of the vitamin tablets, but at no point was a safeguarding alert made. Other protective measures which might have been considered were a mental capacity assessment and Best Interests Decision in relation to Mr F's non co-operation with home carers.

RECOMMENDATION 9

That the SCR features in refresher training for Calderdale and Huddersfield NHS Trust, Greater Huddersfield Clinical Commissioning Group, Kirklees Council, South West Yorkshire Partnership NHS Foundation Trust, Kirklees Healthwatch, Carers Emergency Support Services and West Yorkshire Police and in the Safeguarding Adults Board's training programme. Multi-agency workforce training is critical if professionals are to understand the impact of dementia and its implications for people's lives

Dementia Strategy

Finding

There is an important observation to be made about policy issues in general and their enactment in Kirklees. Agencies have a responsibility to turn policy into practice through procedure, professional expertise and managerial oversight. Documenting progress in policy implementation is useful in holding professionals and agencies into account. However, the consequences of failing to make progress lead to disillusionment among the very population whose commitment and endorsement is essential.

Finding

Mr F's diagnosis of dementia should have given him and his family access to a clear pathway for information, advice and support planning. This did not happen.

RECOMMENDATION 10

That the cross sector leadership body in Kirklees revisit their Dementia Strategy and its implementation to ensure that (i) service provision aligns with strategic objectives and (ii) people living with dementia and their families experience an integrated service, most particularly when they have diagnosed physical co-morbidities.

RECOMMENDATION 11

That Kirklees undertakes to become a dementia-friendly locality.