

A SAFEGUARDING ADULT REVIEW REPORT

**COMMISSIONED BY
ROYAL GREENWICH
SAFEGUARDING ADULTS
BOARD**

MR. F.

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Introduction

1.1 This report covers the findings and recommendations of the Safeguarding Adults Review, undertaken on behalf of Royal Greenwich Safeguarding Adults Board (RGSAB) relating to a death of an adult in 2017(referred to as Mr F throughout this report to preserve his anonymity).

1.2 The Safeguarding Adults Review is not intended to attribute blame but to learn lessons from this case and make recommendations for change that will help to improve the future safeguarding and wellbeing of adults at risk in Greenwich in the future.

1.3 The review was conducted in the light of the following legislation;

The Care Act 2014-Section 44 Safeguarding Adults Reviews

The purpose of Safeguarding Adults Reviews is described very clearly in the statutory guidance as to 'promote effective learning and improvement action to prevent future deaths or serious harm occurring again'.

The aim is that lessons can be learned from the case and for those lessons to be applied to future cases to prevent similar harm re-occurring.

The Department of Health Care and support statutory guidance – published to support the operation of The Care Act 2014, states¹:

'14.163 Safeguarding Adults Boards (SABs) must arrange a Safeguarding Adults Review (SAR) when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked more effectively to protect the adult.

14.168 SARs should seek to determine what the relevant agencies and individuals involved in the case might have done differently that could have prevented harm or death. This is so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again. Its purpose is not to hold any individual or organisation to account.

1.4 Why was this case chosen to be reviewed?

This case came to the notice of the Safeguarding Adults Evaluation Sub-group (SEG) following an inquest by the Coroner. Mr F was found dead by his father in his flat on 6 March 2017 with swellings to his foot and knee. The cause of death was Septicaemia, Pyelonephritis associated with ascending Urinary Tract Infection and an infected Leg Ulcer.

Mr F was a 38-year-old man who had lived independently in his own adapted accommodation. He was diagnosed with Spina Bifida in childhood (resulting in

¹ <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support->

deformation of his feet and severe pain, difficulties in mobilising independently and incontinence) and hydrocephalus (resulting in interventions to fix shunts in his skull to release fluid from his brain). Mr F had a history of severe leg ulcers, urine tract infections (UTIs) and self-catheterised. His case was chosen for a review as the RGSAB felt this could reveal useful learning about multi agency practice in the management of similar long-term health conditions in the borough.

1.5. Family composition and history

Mr F was born in Greenwich, and was cared for in a special care baby unit. He was born with Meningomyelocele (Spina Bifida) and bilateral talipes (where feet are bent inwards) in 1979. He then attended local mainstream schooling. Had eye surgery in 1986 to correct slight optic nerve cupping. The family then moved to the North East in 1999, where he attended a school for children with physical disabilities, before returning to the Local Area to live with his father in 2007, after the death of his mother. The deformation of his feet as a result of his condition caused him severe pain and difficulties mobilising both inside and outside the home. He was also diagnosed with hydrocephalus and had shunts remaining in place to release fluid from his brain. In addition he was doubly incontinent, using incontinence pads and self-catheterisation to manage this. He relied on the daily support of his father to help meet his daily support needs and lived with his father until allocated an adapted housing association flat through the Housing Dept.

His father continued to visit him on a regular basis to assist him at home and take him out. At the time of his death, his father was visiting him weekly, although Mr F. did not always accept offers of help from his father or services.

1.6. Timeframe, Terms of Reference and Scope

This review covers key periods of contact with Mr F. from his return to the borough in 2007 until the time of his death in 2017. The agreed Terms of Reference for the Review cover the following areas;

To identify whether there were any gaps or deficiencies in the care, support and treatment of Mr F.

To identify if Mr F's death was predictable and/or preventable.

To identify areas of best practice, opportunities for learning across organisations and areas where improvements to services might be required which could help prevent similar incidents from occurring.

Review the care and support, treatment and services provided by the local authority, hospital, GP, and any other relevant agencies to Mr F with specific attention to inter-agency working in relation to safeguarding Mr F.

Review whether local Safeguarding Adults Policies and Procedures were properly followed, addressing the six principles of safeguarding.

Review the effectiveness of care planning for Mr F.

Review and assess compliance with local policies, national guidance and relevant statutory obligations.

Review the issues raised by the Coroner's Inquest and any actions taken following this.

Provide a written report to the Royal Greenwich Safeguarding Adults Board that includes measurable and sustainable recommendations.

1.7. SAR Methodology

The methodology for this SAR was through a collation of Individual Management Reviews, with this Independent Overview Report provided by an author who is fully independent of any agency that was involved with the case. The Overview Report will be submitted to the SAR Panel initially for their approval and an action plan.

1.8. Individual Management Reviews

Individual Management Reviews are a means of enabling organisations to reflect and critically analyse their involvement, to identify good practice and areas where systems, processes, or individual and organisational practice could be enhanced. They are key learning tools used in several of the Safeguarding Adult Review methodologies and other similar reviews such as Domestic Homicide Reviews and Serious Case Reviews. They can be used in a multi or single agency environment.

1.9. Agencies that had involvement in the case and submitted IMRs for learning in this case were;

A NHS Foundation Trust, Diabetes and Wound Care.

Assessed and provided treatment to Mr. F. upon his return to the borough via outpatients' appointments at Queen Elizabeth Hospital, he was also subsequently referred for specialist Neurology, Orthopedic and Vascular Team assessments, prior to his discharge from the service due to his non-attendance in 2010. A summary of their involvement was submitted for the review.

A NHS Foundation Trust – Community Podiatry

Mr. F. Was under the care of the Wound Care Podiatry team (at this time the service was under a Community Health Service not a NHS Foundation Trust) from the 7th of December 2007 until the 25th of June 2009. He was seen as in the outpatient clinic for the assessment and treatment of foot ulcers. He was seen weekly or fortnightly. A separate IMR was submitted by this service.

Metropolitan Police Service.

The police were called to Mr. F.'s address by his father, upon the discovery of his body and submitted a brief report of their involvement for this day only, as they had not had prior contact with him.

The GP Surgery

Mr. F.'s GP practice had contact with him when he returned to the area and referred him for the above specialist healthcare services. He was last seen in person at the surgery in 2008, although continued to receive repeat prescriptions for catheters until the time of his death. No IMR was submitted by the GP, although a letter and a scanned copy of his medical records were sent.

Royal Borough of Greenwich Adult Services Department

Mr. F. was assessed for his care needs in 2008, prior to his move into his own accommodation, but did not require services at this time, due to his father caring for him. His needs were not reassessed after his housing move, although was seen again in 2012 by an Occupational Therapist Assistant to review his use of equipment. Adult Services submitted an IMR, and copies of contacts and assessment records were found following a search of the client database (Framework i)

1.13 Methodological comment and limitations

It was a significant challenge that the Review did not start until over 2 years after Mr F.'s death and it took time to obtain agency chronologies. Furthermore due to the limited involvement of statutory services there was little material available for the Review, with no contact from most services after he moved to his own accommodation in 2010. Information from his Father would have been very useful to be included, however, he was not available for comment. The SAB Manager made a series of attempts to contact Mr F.'s father during the review by a different methods (telephone calls and messages, e-mails and hand delivering letters to his address). Unfortunately, he did not respond to these and so it is acknowledged that this is a gap in practice for this review and a lost opportunity to incorporate his views for potential learning from the case.

Therefore the learning from the limited available material will cover consideration of the decisions and subsequent consequences for Mr F. of the absence of follow up after he moved from living with his father and into his own accommodation.

1.14 Reviewing expertise and independence

An independent consultancy company (MSH Training & Consultancy Ltd) undertook the SAR and appointed an Independent Lead Reviewer. All relevant documentation was then shared with and scrutinised by the Independent Lead Reviewer, to compile an Independent Overview Report. Mick Haggart is the author of this Overview Report, which has been completed on the basis of submissions of Individual Management Reports and other reports (outlined above).

In addition a separate independent medical report was commissioned as part of this review, in order to offer analysis on the health care needs of Mr F. and services that he received. Dr. D. J. Richard Morgan MB BS, FRCP, undertook this. (Consultant Physician & Senior Lecturer in Medicine, Imperial College Faculty of Medicine, Chelsea & Westminster Hospital NHS Trust).

Dr Morgan has been the Consultant in Charge of a specialist multi-disciplinary clinic for adults who were born with Spina bifida and/or Hydrocephalus for 30 years. This specialist clinic provides annual and emergency follow up for patients with this complex congenital abnormality, which causes variable neurological, mobility and continence problems for life. The service was established at the Chelsea & Westminster Hospital in 1990 and provides services for patients with this condition across London, although Mr F. had not been seen by this service.

1.15 Acronyms used and terminology explained

Writing for multiple audiences is always challenging. In Appendix 1 we provide a section listing any abbreviations used to support readers who are not familiar with the processes. In Appendix 2 language and terminology of medical and safeguarding work is explained and referenced. References are also made to key guidance or research, in footnotes.

2. Summary of the Case and appraisal of practice.

The section below sets out a summary of the multi agency chronology of service involvement in this case. The independent author collated this chronology from the IMRs, individual agency chronologies and other reports, which were submitted by the agencies participating in this Review (see 1.9. above). The chronology was then divided into Key Practice Episodes (KPEs), which will then be analysed for learning in Section 3.

2.1 First Key Practice Episode (June 2007- April 2010)

Mr F was living with his father during this time and had a number of contacts with both his GP and various health and social work professionals. He was on a waiting list for his own accommodation and in June 2009 he moved into his own tenancy.

In November 2007 he was assessed by a community OT, who identified problems with walking, standing and recommended special shoes due to his feet problems.

He was referred to Housing for his own accessible accommodation and back to his GP for health tests, as he had headaches and it was unclear whether his shunt was working properly. He received no care services during this time, was isolated socially and dependent on his father to meet his care needs. He received High Rate DLA and had a mobility scheme car, which his father used to take him out. His main avenue for socialisation was accompanying his father to a local social club once a week.

In December 2007 He was assessed by podiatrists for bespoke footwear and treated for a pressure ulcers (infection and necrosis) on his feet with antibiotics & dressings. These were overseen on several appointments by a wound care podiatrist. These improved with treatment during December, although he was referred to a vascular surgeon as the wound on his right foot then was described as deteriorating, due to weak pulse in his foot.

A vascular surgeon saw him in January 2008; a pulse was not found, dressing wounds continued with a review scheduled for 3 months time and a duplex scan. A neurologist reviewed his headaches at this time. He also had a brief hospital admission for assessment following abdominal pain and catheter urine retention (outcome of this was not known) although a community neurology matron was involved, with a remit to reduce admissions. He had on going treatment from the wound clinic for his foot in February (his shoes were thought to be the problem) and his scan results were ok, his left foot had healed and his right was improved.

In March 2008 he had a further bacterial infection of his right foot (no record of any antibiotics given), which resolved and he was seen again in April when the wound was redressed.

In May his CT scan results showed the shunt was positioned correctly and his neurologist wrote to inform his GP of this and a 6-month follow up.

He was then assessed by Local Area Adult Services for an Overview Assessment of his care needs by a social worker, at this time he was on the waiting list for his own accommodation. His difficulties walking, pain in his spine/back and incontinence were noted, as was his social isolation due to the inaccessibility of his father's house and his father spending time outside the house with his girlfriend.

Mr F had eligible needs for care, but was happy with the care provided by his father and didn't want services involved, until he moved to his own flat. His father was also happy to provide this care and did not want a carer's assessment at this stage. He had a Motability scheme vehicle to take Mr F out (e.g. to the pub to see friends), as he was unable to use public transport and high rate DLA. He got around inside on a tea trolley and used a wheelchair when outside, he expressed a wish for greater independence and declined care, until his own accommodation was available. Mr F did not have any social care services in place at this time, or any set up when he did move into his own housing.

In June 2008 he had an assessment with orthopaedics, which recommended orthotics and new boots. It was noted he had callouses on his knees from crawling, that his feet were numb and that surgery may be required, he was to be seen in 6 months for follow up review. Mr F did not attend appointments with neither the community rehab service, nor a dietician and was discharged from these services in July. He also did not attend neuro-appointments in Oct 2008.

Mr F had a new wound on his right foot, which was dressed at hospital and antibiotics were prescribed, with dressings requested from his GP. He did not attend a follow up neurology appointment in Jan 2009 and was also discharged from this service. He had further dressings and more antibiotics for this wound in February 2009. By March his wound had improved but had a new wound on his left foot, with more antibiotics prescribed in April 2009. He did not attend his next appointment but was seen again in May 2009, with the wound reassessed and cleaned. He missed his appointment in May and was seen in June 2009.

He was seen for a review of his left foot in June 2009, having completed another course of antibiotics, the area around the wound was red and swollen and more antibiotics were prescribed following a request from Podiatry by his GP. He had a further appointment in June and his wound was debrided, cleaned and dressed with on going follow up in July, which he did not attend. He was discharged from the local hospital clinic in Sept 09, for follow up in a community clinic (Fairfield).

He did not attend his appointment at Fairfield in October 2009, a message, text and letter was sent to him, as was standard practice by this service. He also did not attend his appointment in November 2009 for Orthopaedics and was discharged, with no follow up appointment although a letter was sent to his GP.

2.1.1. Appraisal of Practice

During this period of the chronology Mr F. was residing with his father, who supported him to attend the various health and social care appointments. The lower limb wounds were assessed and successfully treated through these outpatients' appointments. However, due to his non-engagement over this time he was discharged from all specialist services and did not receive on going follow up. Although the interventions were appropriate to his needs, there was a lack of any assertive follow up when he failed to attend follow up appointments.

He was presumably thought to have capacity for the decisions re; non-engagement, although no assessment of this was undertaken or consideration of the impact of his diagnosis on his insight into this various needs for on going care and treatment. This was a gap in practice, which will be explored in more detail in the learning set out in Section 3. There was also a lack of information sharing between health and social care, which became more significant at the point when he was re-housed into this own accommodation during the next period of the chronology. In particular he was not followed up for on going risks around his pressure areas from primary care or community health services.

2.2. Second Key Practice Episode (April 2010- June 2012)

Mr F. was re-housed into his own accommodation in 2010. GP notes in April 2010 noted a letter from Podiatry (unclear if this was the same letter as in above correspondence, referred to in Section 2.1 which was sent to the GP from Podiatry in June 2009). He was prescribed (on an on going basis) for 60 catheters from his GP, every 2 months from this point onwards. In May 2010 it was noted there had been no contact with Mr F with podiatry from either the local hospital, or community services, or orthopaedics.

He was then finally discharged from community podiatry due to no contact in August 2010. He had no recorded contact with any service for the rest of 2010 or 2011, apart from the repeat prescriptions from his GP for 60 Catheters every 2 months. He had been sent a letter from his GP in Nov 2011 as by then he was known to have moved out of the catchment area into his new accommodation, but a further letter in Feb 2012 said would be kept on the surgery list. In May 2012 his repeat prescriptions for Catheters were increased to 120 at a time, sufficient for 4 months self-catheterisation, but with no reviews arranged.

2.2.1. Appraisal of Practice

The key change during this period was that the Housing Dept. allocated Mr F. his own adapted ground floor flat accommodation. Despite the change in circumstances it does not appear that the Housing Dept. alerted any other service of his move, or any on going needs for reassessment of his needs as

he was no longer living with his primary carer (his father). Due to a lack of information from his father it was not known what care was given to him during this time by his father. It was known that he had eligible care needs from his earlier assessment and Adult Social Care Services were planning to reassess these upon his move to independent housing. However, as there were no records to indicate that Adult Social Care were told about his move, no assessment was planned or undertaken. There were clear risks related to Mr F.'s lack of mobility inside and outside of his flat, but the exact nature of these were never explored.

Furthermore, his ability to attend appointments was clearly affected by his living alone and as above, he was not followed up directly, instead closed to all agencies apart from his GP, due to no-response to letters. It was also not clear that health or social care were aware of his move, so may not have been writing to him at his change of address.

In addition the relationship between the cognitive and behavioural impact of his Spina Bifida was not taken into account, as to whether he was able to identify when his physical health started to decline, exacerbating the risks of pressure ulcers being more likely to develop. It was known that Mr F. wanted to be independent and may have been faced both practical and psychological barriers to seek the help he needed. As he did not seek help it appears that he was deemed to be no longer in need of services, when in fact his need for monitoring and assessment undoubtedly increased subsequent to his move. There was however one further scheduled review of his needs 2 years later, by an Occupational Therapist Assistant during the next phase of the chronology. It was unclear from the notes what prompted this visit, as this was recorded as a scheduled review, albeit 2 years after his last OT contact and at what point his new address became known to Adult Services.

2.3. Third Key Practice Episode (June 2012- Feb 2017)

Mr F had a home visit for a planned review of his equipment by an Occupational Therapy Assistant (OTA), which was a standard and scheduled review for equipment that had been provided to him (a rise/recliner chair). He was noted to have had a dramatic increase in weight by 3 stone and did not use the rise function of his chair, instead crawling to it and lifting himself into it, then dropping from it onto the floor. He was advised of the risks of this and agreed to a referral to the Adult Social Care Team, which was made by the OTA in June 2012 for advice on safer transfer techniques. It was unclear what happened about this referral, but a Physiotherapist saw him in September 2012 (no details of this were available to the Review) and he was sent an appointment letter from the Adult Services Team in Sept 2012. He did not appear to respond to this letter and there was not further follow up on the referral, which was presumably closed due to his lack of response.

There are no recorded further contacts from any professionals, apart from the repeat prescriptions for 120 Catheters every 4 months, for the next 5 years. A letter requesting a medical report from the Job Centre Plus about his benefits was sent to his GP in April 2016, which appears to have been done by the GP

without seeing Mr F. In July 2016 there was a letter on file about a Blue Badge renewal, again it appears Adult Social Care processed this without seeing Mr F.

2.3.1. Appraisal of Practice

By this stage Mr F. had largely disappeared from the caseloads, or responsibilities of any agency, although due to the Adult Social Care standard review model he was seen to check he was using provided equipment safely.

The outcome of this assessment was that he was not using equipment appropriately, putting himself at risk inside his home. There was some good practice by the OTA, whereby she did identify this risk and the subsequent need for a re-assessment, which did not take place. As his case was closed to Adult Services at this point, this was identified as a missed opportunity to more thoroughly consider his circumstances at home, after the referral was made. This was not responded to by Mr F and no review or reassessment ever took place, although the reason for this was not clear from records submitted to the Review. I have made an assumption that this was not pursued due to his lack of response, although if this was the reason it was not recorded as such at the time, nor subsequently. Decision-making about the referral is therefore unclear.

Other missed opportunities during this time were that his eligibility for a Blue Badge and Welfare Benefits were requested from both his GP and Adult Social Care, to check he was still entitled to these. Both agencies confirmed he was still in need of and eligible for these, but neither took the opportunity to see him when these were confirmed. They appear to have been completed as an administrative function but did not prompt a need to check this through a visit to Mr F. If this had been done it would have given health and/or social care services an opportunity to meet and re-assess his circumstances, needs and risks associated with living alone.

During this time there was no information as to what care his father was attempting to offer, nor what Mr F.'s response was to any social care. Finally, the GP practice increased the number of catheters given to him by repeat prescription but as in the preceding episode no check was ever made as to whether this mode of self care was still appropriate and successful.

2.4. Fourth Key Practice Episode (03 March 2017-06 March 2017)

Mr F's father visited his son on Friday the 3rd March to help him sort out his flat, but Mr F refused to let him in. His father advised him to go to hospital, as he appeared pale and looked unwell, but he refused to go. His father then visited him again on Monday the 6th March. On this visit Mr F's father called emergency services after visiting and finding Mr F. deceased on the floor of his front room. Both the Ambulance Service and Police attended his flat, he was pronounced dead by paramedics at 9.12, with evidence of rigor mortis and post mortem staining. When found by police he had a blanket over his

bottom half and was naked beneath this. He had two large swellings, one to his right foot, which was infected, and the other to his right knee, which appear to be rotting, and infected. There was a large hole where his knee was and faeces smeared over both his flat and his lower body.

His father told police that Mr F. lived on his own and was not part of any care plan and did not have a carer. His father would come to his address once a week to make sure he was fine but Mr F. never told him if there was anything wrong. Every time his father would ask, he would reply saying no. His father said Mr F can be very stubborn and never ever asks for help. The last time he got any medical help was 2years ago.”

The Coroners recorded cause of death as Septicaemia and Pyelonephritis associated with ascending Urinary Tract Infection and infected Leg Ulcer.

2.4.1. Appraisal of Practice

The account of emergency services when called to Mr F’s address, by his father clearly revealed a significant and long-standing struggle to cope with his own care needs by Mr F. This appears to have significantly contributed to his death, due to the physical health consequences caused by his self-neglect. It would appear that the serious pressure ulcers of his legs became infected and was likely to have contributed to his Septicaemia, also that there had been a problem with his prolonged self-catheterisation, which may have caused the urinary tract infection.

As no service had seen him in the preceding 5 years (since his OTA assessment in 2012) it was unclear as to the nature and degree of his self-neglect. It appeared likely that he was not able to manage his incontinence and maintain an adequate standard of self-care; questions remain as to whether this was in any way wilful, or as a result of the neurological and cognitive consequences of Spina Bifida. Clearly his isolation within his flat also contributed to his decline and his ability of his father to care for him seems to have been compromised, both by Mr F’s response to his father’s offers of support and by his father’s ability to visit frequently enough to provide sufficient support. When they lived together his father was providing hands on care on a daily basis but after Mr F moved out this reduced to weekly visits.

3. Analysis and Learning from the case

This section is a summary of the independent medical expert review by Dr Morgan of the impact of Mr F's medical condition and the suitability of service he received during the period under review. The full (anonymised) version of Dr Morgan's report can be found in the appendices for further reference.

3.1. Overview of Impact of Spina Bifida on Mr F.

Mr F was born with the congenital neural tube developmental abnormality called Spinal Dysraphism, commonly referred to as Spina Bifida. This condition often results in significant disability affecting many aspects of an individual's development and subsequent health.

This includes:

- Mobility problems due to neurological disorder of motor and sensory input to the limbs especially the lower limbs.
- Cognitive and emotional development problems, especially when hydrocephalus is present and even when shunted.
- Neurogenic bladder and bowel incontinence.
- Pressure ulcer development due to absent sensation in legs and saddle area
- Obesity and related medical conditions due to immobility, which reduces exertional activity as patients, become older.
- This includes Respiratory failure partly from chest deformity and due to central respiratory centre depression from the later effects of treated hydrocephalus.
- Psychosocial related difficulties related to disability, limited employment opportunities, prejudice and discrimination, social isolation and access to healthcare resource provision problems.

It was apparent from the review of Mr F's contact with services that he exhibited all of the above effects of his condition. However, both Health and Social Care services were poorly equipped to mitigate the impacts of these consequences for Mr F, which were clearly exacerbated when he was discharged from all services and left to cope with these alone, but with some weekly visits from his father.

3.2. Summary of information prior to the period under review

Mr F's Spina Bifida was apparent at birth with a visible lumbar myelomeningocele. This was repaired on the first week of life at a local Children's Hospital. Mr F then moved away to live in the North East during his childhood. During this time, he developed divergent squint and had ophthalmic surgery to correct this. Squint is a common feature of hydrocephalus related problems. Pallor of the optic discs was observed – which suggests optic nerve atrophy following raised intra-cerebral pressure, because of unrelieved hydrocephalus. It also results in visual impairment and reduced acuity.

Mr F was diagnosed with hydrocephalus, which was managed by shunt insertion. This was complicated by several insertions/reconnections. Intellectually he attended special schooling, and apparently did not achieve any secondary Examinations. He did not ever manage to have any employment. Mr F had problems with both legs from infancy. This resulted in walking difficulty and the need for special shoes.

3.2.1. Analysis and Learning from the First Key Practice Episode (June 2007- June 2010)

In 2007 Mr F (aged 28) returned to London with his father, following the death of his mother. Foot ulceration was present and managed by dressings in the community. He walked with the use of frames, tea trolleys, or wheelchairs latterly. He tended to crawl about at home and developed callouses on his knees as a result. Mr F had multiple foot problems characteristic of a paraplegic patient:

- Pressure ulcers – 2007/8 – right foot – seen at a local hospital. Osteomyelitis suspected.
- Recurrent cellulitis occurred in 2007 requiring repeated antibiotics and regular dressings and wound cleaning by district nurses of attendance at clinics.
- Leg swelling and colour change from lymphedema – often suspected as vascular disease but normal arterial flow seen.
- Chronic low back pain
- Mobility difficulty – wheelchair assessment and provision
- Special shoe provisions
- Bathing facilities – access to shower/bath or wet room.
- Bowel continence had been satisfactory in childhood and manageable with a healthy high fibre diet. In 2008 Mr F had episodes of soiling and incontinence requiring a pad for protection ever since.

In 2008 Mr F was referred to the Neurology clinic for review because of intermittent headaches. The letter from the consultant stated that Mr F had not had any review for some time. There were also symptoms of shortness of breath, weight gain, poor mobility. Headaches were not indicative of pressure effects. No examination findings are recorded. CT brain scan was arranged and subsequently reported as showing large ventricles with the shunt position 'okay'. Six monthly follow-ups advised, but attendance was poor with frequent cancellations by Mr F over subsequent years.

Socially in 2008 Mr F lived with his Father in a house with steep step access and railings to aid Mr F, which had poor wheelchair access. It was described as a residential location. An application was made for independent rented local authority accommodations to allow him independent living separate from his father who now had a new relationship. He was a smoker. Father had a Motability car and drove Mr F about as needed. Mr F received high rate DLA benefits on account of his disability. He attended a local pub for social activity

to watch football with friends. He declined offers of social care for shopping and personal care.

3.3. Analysis and Learning from the Second Key Practice Episode (April 2010- June 2012)

Mr F moved to independent living in a purpose built flat fully adapted for wheelchair user with gated access. His attendance at healthcare appointments became almost non-existent. GP services provided repeat prescriptions for urinary catheters for ISC.

Further episodes of foot infection during this period, with orthopaedic and podiatry follow-up after acute illness. Also, non-attendance at review appointments, and some community care. Bladder & Bowel continence is often a problem for Spina Bifida patients. Mr F had urinary spontaneous voiding and was taught Intermittent Self Catheterisation (ISC) which appears to have been reasonably successful. Mr F had intermittent urinary tract infections managed with antibiotics as required.

Hydrocephalus causes long-term cognitive impairment. Even with preserved IQ and normal cognitive screening there are often significant impairments in functional executive performance. This deficit may manifest in poor decision-making, impaired short-term recall and inappropriate behaviour. Resulting mental health problems can then become apparent with anxiety and depression frequently developing. These features are all compounded by social isolation.

He should have received community care and physical reviews of his various medical system conditions -urological, neurological, orthopaedic/podiatry and district nursing for his leg swelling (lymphedema) and ulceration. Specialist nursing input from a Continence Nursing and Tissue Viability should have been involved, and appliance/orthotic services and the local wheelchair clinic regular assessment provided. Problems such as possible osteomyelitis of the bones in the feet when ulceration occurs require multi-specialty cooperation, vascular surgeons, orthopaedic surgeons, plastic surgeons and microbiology, as well as appropriate imaging. MRI scanning provides the best investigations, and plain x-rays only show destruction relatively late.

There was a clear deterioration in mobility as a result of Mr F's move into independent living, despite having a flat with modifications to accommodate his disability. This was undoubtedly brought about by the circumstances of his community care. If Mr F had engaged with regular care review of his medical and social health, with respect for his autonomy but consideration for his disability both physical and cognitive, providing a consistent supervision it is my opinion that this deterioration would have been avoided.

3.4. Analysis and Learning from the Third Key Practice Episode (June 2012- Feb 2017)

Neurologically Mr F had been assessed in 2012, and Brain Imaging in the form of a CT Brain scan had shown chronic megacephaly (Enlarged lateral ventricles within the Cerebral cortex) with a normally placed shunt. The headaches he complained of were considered not to be due to raised intracranial pressure, or shunt malfunction. No cognitive evaluation was recorded. There is no detail of Mr F's academic achievements as a young man/child. It is not clear whether any attempts were made to find any occupation or voluntary activities for him in his adult life. His main support and carer was his father who clearly maintained a significant degree of involvement in Mr F's care even when he moved out of the Father's house in 2010.

Home visit assessment by an Occupational Therapist Assistant in June 2012 recorded significant weight gain of approximately 3 stones to 16 stone and a height of 4 foot 10 inches (BMI of 47 – morbid obesity). At risk behaviour was recorded, falls risks and transfer risks were seen. MR F declined offers of help.

It should be noted that many 'older' patients with Spina bifida become less mobile with time, even if they were ambulant formerly. This is due to a combination of factors. Degenerative spinal disease is a major factor. The developmental deficiency in the spinal architecture makes for premature osteoarthritic complications. When a patient is overweight this compounds their situation. 90% of patients with Spina Bifida are overweight. Mr F had morbid obesity (BMI >40) and it is probable that he would have become electric wheel-chair dependant within a few years.

Many Spina Bifida patients living alone (especially men) tend to live off convenience foods such as take-always and ready prepared microwave able meals. Dietician input could help, and weight losing support services also beneficial. Morbid obesity patients should be considered for gastric by-pass surgery and monitored for the development of diabetes. Patients who are housebound and eating poor diets are frequently vitamin deficient, which increases risk of ill health (fractures/osteomalacia from vitamin D deficiency, low foliate and iron levels causes poor wound healing).

Apparently thereafter for approximately five years Mr F was not seen or assessed by any healthcare or social professional. Applications for Benefits renewals were made on his behalf also without being seen. His care during the last five years of his life from medical and local authority social care services appears to have been minimum, in part due to Mr F's own wishes and refusal to attend follow-up appointments. This lack of regular assessment by community and secondary health care services may of contributed to the development of severe complications, which caused his collapse at home.

Inadequate regular review of the urinary tract by consistent medical assessment and investigations failed to identify the significant potential for sepsis, which could have been prevented. Patients with Spina Bifida and neurogenic bladders are known to be at high risk of urinary tract sepsis and

because of immobility and lack of sensory neurological function they do not feel symptoms in the same way as 'normal' patients.

This should have been identified as a high risk of sepsis being present on both the General Practice and community records. Patients with neurogenic bladder who are performing ISC should be reviewed annually, with urine culture, blood renal function tests and renal tract imaging – usually by ultrasound with pre and post micturition bladder volumes measured. Most patients attend a local urology service, often nurse lead for this annual review. The fact that this was not identified nor addressed by Mr F's GP was clear gap in practice.

There are no records of Mr F's respiratory function. However, his hydrocephalus and obesity are likely predisposing conditions, which often result in mid-life respiratory failure in Spina Bifida patients. Obstructive sleep apnoea requiring NIV (Nocturnal Intermittent Ventilation) is not uncommon in our cohort of patients. This can contribute to fatigue, somnolence, depression and inertia, which is insidious in onset. Mr F complained of shortness of breath in 2012, which was never fully evaluated.

3.5. Analysis and Learning from the Fourth Key Practice Episode (03 March 2017-06 March 2017)

On Friday 3rd March 2017 Mr F's Father visited him to ' help him sort out his flat', but Mr F refused to allow his father to come in. His father was concerned that Mr F looked unwell, and apparently advised Mr F to go to hospital, but this was refused. His father said he would return after the weekend. On Monday 6th March 2017, Mr F's father found Mr F dead lying on the floor of the flat with Rigor Mortis present. Mr F was unclothed from the waist down, and his lower body covered with faeces. His right knee was ulcerated through to the knee joint. The right foot was also infected and swollen. Mr F was a patient with Spina Bifida & Hydrocephalus, neurogenic bladder and bowel with paraplegia. He had addition significant co-morbidities of morbid obesity and lymphedema with leg ulcers at the time of his death from Septicaemia due to urinary tract infection and leg ulceration.

Medical services in hospitals today are pressurised into maximising efficiency of outpatient management, and inpatient admissions are increasingly restricted to emergency issues, with the imperative to discharge patients to the community as soon as possible. Admissions for prolonged treatment for infected leg ulceration or pressure ulcers are infrequent, and continuity of care is limited. Many clinicians fail to appreciate the effort and difficulty it requires for a patient with mobility difficulties to attend for outpatient clinics. One nonattendance results in discharge from the system.

Dr Morgan noted that one such event happened when Mr F was an inpatient as an emergency and could not come to clinic. This is a failure by the hospital medical services to recognise the difficulties of disabled people with long-term neurological conditions such as Spina Bifida & Hydrocephalus, as was the

case for Mr F. It then falls to their carers or General Practitioner or Adult Services to pursue their care, as the patient often feels neglected, and that that they do not see any benefit from the attendance in hospital. Improving their health situation requires persistence, encouragement, flexibility and developing a relationship with the individual.

Ideally this care plan would be provided in a multi-disciplinary clinic situation, maximising the expertise of various specialists both medical/surgical and nursing and therapy (physiotherapy and occupational therapy) with social services input in a whole day annual review with appropriate investigations arranged to occur on the same day. This would have ensured that effective investigations happened and decisions about his care were agreed, and not frustrated by his non-attendance.

3.6. Specific responses to Questions for Review.

3.6.1. How did Mr F's specific medical conditions of Spina Bifida & Hydrocephalus contribute to or affect his decision making and insight into the nature of his health and care needs?

Hydrocephalus even when decompressed and treated with a shunt causes variable intellectual compromise. This manifests with short-term memory recall difficulty, and executive functioning problems. Some patients have a frontal lobe syndrome with a degree of 'belle indifference' attitude, which may result in them declining offers of assistance or attending clinical follow-up in the hospital or community. Patients with hydrocephalus may appear mentally competent but can be overconfident about their ability to manage their health care needs until a crisis develops.

Dr Morgan noted that a community OT described Mr F as very articulate in 2007, and elsewhere that he had some memory difficulty, but it was not a problem. This was true when he lived with his father who as his fulltime carer provided Mr F with comprehensive support, including prompting him to attend appointments. Once Mr F moved away from his father into independent living, this supervision was lost and a downward spiral in health and social care begun.

A second factor related to the Spina Bifida effect on Mr F's response to illness is that patients with spinal injury are insensitive to pain below the level of the spinal damage. This means they do not feel the pain of injury or inflammation in their extremities, and infection becomes established with systemic effect before it is realised that they are ill. This may be from skin infections, pressure ulcers, trauma from poorly fitting shoes/appliances, burns from hot water/bottles/proximity to fires etc, and from internal infections such as urinary tract infections. Patients can fracture bones without experiencing pain, and minor trauma (banging legs when going through doors) may result in significant injury. It is also often surprising that medical staff and nurses are not aware of this lack of sensation and its implications for the healthcare of Spina Bifida patients.

3.6.2. What should the recommended care be for patients such as Mr F with long term neurological conditions by primary and Secondary care services?

Patients such as Mr F often find that when they reach the age of 16 to 18, and are discharged from children's services that there is no regular medical follow-up, and that they are left to the General Practitioner services, which are not resourced or trained to manage such complex medical and social problems. This then results in crisis management, and referrals to different separate adult system referrals as and when the need arises. This causes a loss of trust by the patient in the care agencies that anyone is concerned about them as an individual. Where children are diagnosed with Spina Bifida, or similar long term neurological conditions and known to Childrens' Services this information should always be included as part of transition arrangements to Adult Social Care Services to ensure that on going needs for care and support continue to be assessed and met.

Ideally care should be multi-disciplinary and multi-specialty, preferably in combined clinics in secondary setting, with pre-planned appropriate investigations. The service should be led by a 'holistic' lead that can provide an overall view and continuity for the patient and his/her community healthcare and social services. Each patient will have priorities, but urology services and continence services for bowel and urine management is a main priority. Neurology expertise is also important, as many Spina Bifida patients have hydrocephalus, epilepsy, and learning difficulties.

Access to neuropsychology for cognitive evaluation is a useful extra. Therapy expertise from a neuro or muscular-skeletal physiotherapist and a community-based occupational therapist will provide invaluable assessment of ADL (Activities of Daily Living) capability. A specialist in Daily Living needs – charity supported or from social services to discuss benefit needs, help with PIP application, independence living opportunities, and to help with employment issues is very helpful. Good secretarial support with telephone/email access to provide contact with patients/carers/fellow professionals for enquiries and appointment arrangements and to deal with concerns between appointments is essential for the service to be effective and efficient, as well as reassuring for patients.

In reality such a situation is only available at Chelsea & Westminster Hospital for Adults, although some Regional Neuro-rehabilitation services are providing a service. Most hospitals will not run such a service, although some System based specialties (Urology and Orthopaedics) have special monthly Spina Bifida clinics, with therapists and expertise focussed on a particular need.

There is a need for multi-agency specialty clinics for neuro-degenerative conditions, with nursing and medical as well as social/therapy input to regularly review such clients and to provide a regular 'MOT' check on the broad aspects of healthcare for such patients. Such services can prevent

deterioration and reduce acute admissions with crisis problems. However, the present contracting processes in the NHS seem not to be in favour of such an approach.

3.6.3. What should have been the suitable treatment/care plan for Mr F, particularly given he received repeat prescriptions for urinary catheters without any apparent health review?

Any patient receiving continued repeat prescriptions should be reviewed six to twelve monthly to assess the appropriateness of the treatment. Mr F's need for catheters was essential and it would be wrong not to continue to supply his need just because of non-engagement with healthcare. However, it should have been possible for someone (GP, District Nursing services, Local Continence Nursing Advisor, Urology services) to make appointments for Mr F or his carer/father to engage for review, and appropriate checks – urine samples for infection, blood tests of renal function and general health at least annually even if asymptomatic, and renal tract imaging to look for obstruction and stones which can result in renal failure. Continence management would improve his self-esteem, and encourage him to engage with socialising, and improve his mood.

Regarding his legs – monitoring for ulceration, and management of lymphedema by compression hosiery, or other measures such as appliances for his feet such as splints/AFOs (Ankle Foot Orthoses) and specialist shoe provisions would make him feel more 'normal' and enable him to go out more. Three to six monthly domiciliary community podiatry was also required. Regular wheelchair clinic review and chair cushion assessment to ensure that sacral pressure ulcers do not develop.

That would have been the minimum healthcare involvement that should have been in place. If that had been achieved, and professionals not been put off by Mr F's non engagement or cancelling of appointments, his progressive deterioration and ultimate death may have been prevented.

3.6.4. Please give your opinion on any impact Mr F's medical conditions could have on cognitive functioning, in particularly his ability to manage access and engage with relevant medical professionals and/or care and support plans/treatment regimes.

Mr F should have been identified as a person with probable impaired intellect from hydrocephalus, and his cognitive function properly evaluated, and mental capacity formerly assessed. He was a person likely to be vulnerable and as such have safeguarding processes in place and on going. His ability to manage his personal health after leaving his father's house to live independently was probably inadequate. As mentioned above Hydrocephalus even after successful shunting causes variable degrees of cognitive impairment, and memory difficulty, and often causes frontal lobe injury, which may result in behavioural difficulty. Patients become passive, and apathetic, uncomplaining and reluctant to engage with family, carers and medical professionals. Refusal to attend for health care management should not be

left unchallenged or accepted as personal autonomy choice without question and this should be considered for reassessment of his health needs and decision making ability under the MCA '05. If his capacity had been identified as impaired then a Best Interest decision would require the views of his next of kin to be included in this process.

3.6.5. Any other comments.

Life expectancy in patients with Spina Bifida and neurogenic bladder is dependent upon the care and supervision the patient receives, and the degree to which he/she complies with medical advice. Spina Bifida patients have a reduced life expectancy, and obesity, pressure ulcers/skin infections also reduce life expectancy. Mr F had a slow decline with lesser level of mobility and quality of life following the move to independent living. Without reviews he was vulnerable to a variety of potential complications, which affected his life expectancy significantly.

3.7. Conclusion:

3.7.1. Mr F collapsed due to septic shock probably from urosepsis. Failure to provide regular medical and social care review for the last five years of his life probably contributed to his deterioration and development of serious pressure ulcers, which was preventable with an appropriate care plan and implementation.

3.7.2. Mr F's congenital condition of Spina Bifida was of a moderate degree, and having survived childhood, his long-term survival was dependent upon his medical, psychological and social support, relating to the problems of neurogenic bladder and bowel continence, paraplegia and pressure ulcer prevention. Hydrocephalus contributed to his cognitive functioning and was probably responsible in part for his nonattendance with medical follow-up after his move to independent living. The severe obesity also contributed to his health problems. His general quality of life and long-term prognosis was probably influenced by the lack of medical or healthcare involvement for the last five years of his life.

4. Findings and Recommendations from Review

This section contains priority findings that have emerged from the SAR. The findings explain why professional practice was not more effective in protecting in this case.

Finding 1.

Patients with Spina Bifida need adequate care and supervision of their condition, as they are at risk of health complications as a result of their condition. For example, as they are unable to feel when they need to go to the toilet they may suffer from urinary tract infections, with a need for regular reassessment and supervision for self-catheterising patients.

In Mr F's case he was taught to self catheterise and issued with a repeat prescription of catheters from his GP, initially 30, then 60, then 120 catheters. He did not have any follow up from his GP practice to check on the outcome of this treatment plan and was not seen by a GP in the surgery since 2008.

As Dr Morgan identified in his analysis, Mr F was at high risk of UTIs, potential blockage of his catheters and renal problems. Pyelonephritis (Appendix 1) was noted by the coroner as a contributory factor in his death, which is caused by a blockage in the urinary tract and leads to an abscess in the renal pelvic region. If he had received regular (6 or 12 monthly) check-ups by his GP, or community health care, this may have been preventable/avoidable or treatable. He had been seen by other health professionals (Podiatry, Physiotherapist) until 2012, but no agency identified the need for monitoring of his catheter care. The risks associated with this treatment plan were exacerbated by his overall poor self care, thereby increasing the likelihood of his contracting an infection or urinary stones and subsequent blockage.

Recommendations For The Board To Consider

1. A review of ISC practice in the borough, by the CCG, to ensure that all patients managing incontinence via ISC are offered a regular medical review by their GP, at least every 12 months. This should be undertaken with reference to the subsequent guidance on best practice as set out in Nice Guidance²
2. If patients do not attend for scheduled health reviews of ISC, then GPs should ensure that they are followed up by an appropriate community health service, such as District Nursing.

² Urinary incontinence in Neurological Disease: Management Of Lower Urinary Tract Dysfunction In Neurological Disease. Clinical Guideline 148 Methods, evidence and recommendations August 2012

3. That patients with urinary and faecal incontinence, who also have a long term neurological condition (such as Spina Bifida) are flagged up on GP health records as being at high risk of complications and always given appropriate advice and support to identify and report any concerns regarding infections etc.
4. Ensure expert advice and consultation on the impact of this condition is available to support health practitioners across local services.

Finding 2

The combined impact of the psychological and physical impairments associated with Spina Bifida, may result in both an increase in levels of health and social care needs whilst also a lack of awareness/insight into of these needs. This puts those adults at a higher risk of experiencing self-neglect, with also a higher potential for suffering more serious harm as a consequence.

For example the lack of awareness of when to eat and drink, the loss of lower limb sensation, leading to not noticing pressure ulcers and if suffering a trauma and an increased obesity from immobility and respiratory disorders.

These aspects of the condition were found in Mr F's case, which were in addition exacerbated by his isolation when living alone and subsequently lost to services, due to his non-engagement.

Recommendations For The Board To Consider

5. Make necessary improvements to the coordination of records between health and social care services to ensure that when clients with Spina Bifida do not attend for appointments they are not subsequently lost to all services. They require assertive follow up in the community for management of their condition.
6. A key link worker for all patients with Spina Bifida living in the community to make regular contact with the client and their family in order to regularly assess/review the risks of self neglect and support for family carers to be provided in line with the requirements of the Care Act 2014.
7. Where adults with Spina Bifida chose to live alone they should be linked into appropriate community services and assisted to attend any outpatients appointments. If patients do not attend appointments a home visit should be arranged prior to decisions being made to discharge the person from the service (e.g. Podiatry, Physiotherapy, Occupational Therapy etc).

Finding 3

Improved links, between Housing and Social Care are needed (at both an IT system and direct level) so that appropriate agencies are correctly informed when a vulnerable tenant with care and support needs is going to be offered their own independent accommodation.

An important aspect of the case for Mr F was his assessment by Adult Social Care prior to his move to his own property, where it was identified that his father was meeting his care and support needs but this needed to be reviewed after his move. However, there were no systems in place to ensure that this took place. It does not appear that this was ever triggered after his move. Partly this was due to the lack of information from the Housing Department to prompt the need for a re-assessment. The impact of this was that after his move his father was no longer in a position to support Mr F on a daily basis.

However, due to a failure to follow this up, by Adult Social Care, further opportunities to explore how Mr F was coping in his new accommodation were not met. His Care and Support needs should have been assessed in his flat and his father's needs for support in his role as main carer should also have been assessed. If this had been done the risks of harm from Mr F's lack of awareness of the impact of his disability could have been assessed and mitigated.

There did not appear to be any systems in place to ensure to reschedule another assessment and there were no links made with the relevant section of the Housing Department to request an update on his housing application. In fact from records submitted for the review it was not clear that Adult Social Care were ever aware of the date or address of his move. The outcome of this was that he was lost to services and effectively left to cope in his flat on his own. His father was also not supported to meet his son's increased needs for care. A further impact of this appeared to be that Mr F did not attend on going health appointments and so the deterioration in his pressure areas, weight, lack of mobility both inside and outside of the house and self catheterisation were not addressed (see Finding 2, above).

Recommendations For The Board To Consider

8. Shared information sharing at a systems level between Housing and Social Care Departments, so that when a housing application is accepted and an offer will be made, on grounds of physical disability, a referral is made for re-assessments under Section 9, 11 of the Care Act 2014.
9. Improve direct links between relevant tenancy support officers and local locality social care services at a level, where tenants whose needs for adapted accommodation due to physical disabilities are part of a re-housing decision. An initial joint visit could then be made by tenancy and social work services as part of a housing offer being processed. A plan could be coordinated to ensure that new tenants with disabilities are followed up for an agreed timeframe to enable them to prepare for a move and to adjust to independent living, with the right care in place (this could follow the discharge to assess model in place when patients are first discharged home from hospital).

10. Coordination of any specialist community health and relevant social care services should also be made as part of this initial transition period following rehousing (led by Adult Social Care Services, with GP input), to agree on a joint plan for on going information sharing and decision making to manage health and care needs during this time. A shared health and social care plan could then be developed, with a lead worker identified to monitor and review this.

Finding 4

Mental Capacity assessments are not usually done for patients where psychological processes are related to a physical disability, which may cause a lack of understanding of the needs for treatment for the effects of the condition. Where patients with this condition refuse services, their ability to take the decision and the potential harmful consequences of this, should be assessed.

Mr F had Spina Bifida and Hydrocephalus from a young age. This can often cause long-term cognitive impairment. As identified by Dr Morgan,

“Even with preserved IQ and normal cognitive screening there are often significant impairments in functional executive performance. This deficit may manifest in poor decision-making, impaired short-term recall and inappropriate behaviour. Resulting mental health problems can then become apparent with anxiety and depression frequently developing. These features are all compounded by social isolation’.

This effect of his disability on his awareness of his needs does not appear to have been considered by any health or social care practitioners, as a possible explanation for his refusal to engage with services. In terms of his capacity these difficulties may have met the threshold for consideration under the Mental Capacity Act 2005 (MCA).

The MCA defines Capacity as,

Section 2(1) of MCA:

“... A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.”

Implications of this definition are that;

- Capacity is decision specific and time specific; &
- Inability must be due to impairment or disturbance.

Given the cognitive problems associated with Hydrocephalus as outlined above this may meet the threshold for the diagnostic test, as being a “disturbance or impairment of the mind or brain” implications of this being;

- First, the impairment or disturbance in the functioning of the mind or brain can be temporary or permanent (s.2 (2)):

- Second, it is important to remember that it is not necessary for the impairment or disturbance to fit into one of the diagnoses in the ICD-10 or DSM-V.7. It can include medical conditions causing confusion, drowsiness, concussion, and the symptoms of drug or alcohol abuse.

To this extent, therefore, the term “diagnostic” test is misleading – the important thing is that there is a proper basis upon which to consider that there is an impairment or disturbance. As Mr. F may not have been aware of the impact of his condition on his care needs, his impairment or disturbance of mind was relevant to his Functional Decision making ability when disengaging from assessments and services.

Functional Decision-making is defined in the MCA Code of Practice (Section 4.14)³

They are unable to make a decision for themselves if the person being assessed is unable to do any of the below,

- **Understand (relevant) information about the decision**
Relevant information includes the nature of the decision, the reason why the decision is needed, and the likely effects of deciding one way or another, or making no decision at all.
- **Retain that information in their mind**
A person must be able to hold the information in their mind long enough to use it to make a decision. People who can only retain information for a short while must not automatically be assumed to lack the capacity to decide- it depends on the decision.
- **Weigh or use that information as part of the decision-making process**
In addition to understanding relevant information, people must have the ability to weigh it up and use it to arrive at a decision. A person may understand the information, but cannot use it as part of the decision-making.
- **Communicate their decision** (by talking, sign language or by any other means). This will only apply if a person is unable to communicate their decision in any way at all.

Mr F may have not been aware of his needs for care and his cognitive functioning may have been further impaired by his disability. This could have affected his ability to use and weigh up information about the risks of not engaging with health and social care services to manage the impact of his condition. As he was never assessed under the MCA the outcome of this was not known, but learning from this case has identified the need to ensure appropriate assessments for decision-making are undertaken in future similar situations.

3

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

Recommendations For The Board To Consider

11. Guidance and training for health practitioners on the role of the decision maker identifying doubt about relevant decision-making (for example consent for/refusal of health care treatment), arising or related to a physical disability prompting the need for a formal MCA assessment.
12. A local policy to support health practitioners in considering the impact of physical disabilities on an adults' decision making, including the duties to assess, where capacity to take a major decision is in doubt (as outlined in 12).

5. Conclusions from Review.

This SAR covers the circumstances surrounding the death of Mr F in his own accommodation from infections related to untreated pressure areas and blockage in his urinary tract. Mr F was effectively housebound due to mobility problems associated with lower leg damage caused by Spina Bifida and Hydrocephalus. His situation was further complicated by the cognitive and perceptual difficulties caused by his disability.

He was not supported by any services despite this and struggled to manage his own care needs, including his double incontinence. He disengaged from all services, was discharged and not followed by any agency after he moved into his own adapted flat. When he lived with his father he was cared for on a daily basis, but after his move this reduced to weekly visits, on at least some of these visits Mr F did not allow his father into his flat. The nature and degree of his self neglect was not known to any service prior to Mr F's death and he had not been seen at home by a professional for the last 5 years of his life.

This review was also compromised to an extent by the lack of any recent professional contacts to consider for possible local learning. The findings outlined above are based on the limited records of contacts prior to 2012 and so may need to be put into context of any service developments since this time. However, the process was useful and greatly assisted by the input of an independent expert in the field of Spina Bifida (Dr Morgan). Dr Morgan has developed a best practice model for multi disciplinary clinic services in this field, which could be useful for specialist medical input to support local front line services for patients like Mr F in future.

As Spina Bifida is a relatively rare condition, affecting on average 1 in a 1000 pregnancies⁴ local services are unlikely to be familiar with the complexities of this disability, especially the possible decisional impacts as well as the more familiar physical impacts. Therefore expert advice on management of this condition may be needed by local health and disability social care services, both for individual cases and to raise awareness of the condition across a range of disciplines that may be providing services to adults with this diagnosis.

It is hoped that the adoption of the recommendations outlined in section 4 of this report by the local Safeguarding Adults Board will prevent a reoccurrence of the circumstances surrounding the death of Mr F in future cases.

The Terms of Reference for the review asked whether Safeguarding policy and procedures were properly followed, however as no safeguarding action was ever taken in this case for Mr. F prior to his death, this question was not relevant for the analysis of the case.

⁴ https://eu-rd-platform.jrc.ec.europa.eu/eurocat/prevention-and-risk-factors/folic-acid-neural-tube-defects_en

Finally, the Terms of Reference for this review included a view on whether Mr F's death was predictable and preventable. From the information provided to the review and the expert analysis of this information it would appear that Mr F's death was a result of a gradual deterioration in his health and functioning whilst living on his own, which ultimately caused a serious infection leading to sepsis and death.

His cause of death, as certified by the Coroner at Southwark Coroners Court, was recorded as

Ia) Septicaemia

Ib) Pyonephritis associated with ascending Urinary Tract Infection & and infected Leg Ulcer

II) Spina Bifida

As he was not seen or followed up by any agency during the 5 years prior to his death no agency had sufficient information to act differently at the time to either predict or prevent his death.

If he had been seen by appropriate health and/or social care services in the final 5 years of his life the outcome may have been different. Therefore it is the view of the report author that his death could have potentially been both predicted and prevented if best practice had been followed in regards to his care and treatment.



Mick Haggard
Report Author
12/06/20

5.1. Summary of Recommendations from the SAR

Finding	Recommendation
1.	<ol style="list-style-type: none"> 1. A review of ISC practice in the borough, by the CCG, to ensure that all patients managing incontinence via ISC are offered a regular medical review by their GP, at least every 12 months. This should be undertaken with reference to the subsequent guidance on best practice as set out in Nice Guidance⁵ 2. If patients do not attend for scheduled health reviews of ISC, then GPs should ensure that they are followed up by an appropriate community health service, such as District Nursing. 3. That patients with urinary and faecal incontinence, who also have a long term neurological condition (such as Spina Bifida) are flagged up on GP health records as being at high risk of complications and always given appropriate advice and support to identify and report any concerns regarding infections etc. 4. Ensure expert advice and consultation on the impact of this condition is available to support health practitioners across local services.
2.	<ol style="list-style-type: none"> 5. Make necessary improvements to the coordination of records between health and social care services to ensure that when clients with Spina Bifida do not attend for appointments they are not subsequently lost to all services. They require assertive follow up in the community for management of their condition. 6. A key link worker for all patients with Spina Bifida living in the community to make regular contact with the client and their family in order to regularly assess/review the risks of self neglect and support for family carers to be provided in line with the requirements of the Care Act 2014. 7. Where adults with Spina Bifida chose to live alone they should be linked into appropriate community services and assisted to attend any outpatients appointments. If patients do not attend appointments a home visit should be arranged prior to decisions being made to discharge the person from the service (e.g. Podiatry, Physiotherapy, Occupational Therapy etc).
3.	<ol style="list-style-type: none"> 8. Shared information sharing at a systems level between Housing and Social Care Departments, so that when a housing application is accepted and an offer will be made, on grounds of physical disability, a referral is made for re-assessments under Section 9,

	<p>11 of the Care Act 2014.</p> <p>9. Improve direct links between relevant tenancy support officers and local locality social care services at a level, where tenants whose needs for adapted accommodation due to physical disabilities are part of a re-housing decision. An initial joint visit could then be made by tenancy and social work services as part of a housing offer being processed. A plan could be coordinated to ensure that new tenants with disabilities are followed up for an agreed timeframe to enable them to prepare for a move and to adjust to independent living, with the right care in place (this could follow the discharge to assess model in place when patients are first discharged home from hospital).</p> <p>10. Coordination of any specialist community health and relevant social care services should also be made as part of this initial transition period following rehousing (led by Adult Social Care Services, with GP input), to agree on a joint plan for on going information sharing and decision making to manage health and care needs during this time. A shared health and social care plan could then be developed, with a lead worker identified to monitor and review this.</p>
4.	<p>11. A local policy to support health practitioners in considering the impact of physical disabilities on an adults' decision making, including the duties to assess, where capacity to take a major decision is in doubt (as outlined in 11).</p> <p>12. Guidance and training for health practitioners on the role of the decision maker identifying doubt about relevant decision-making (for example consent for/refusal of health care treatment), arising or related to a physical disability prompting the need for a formal MCA assessment.</p>

Appendix 1
List of Abbreviations used in the report

Abbreviation	Full Version	Explanation
RGSAB	Royal Greenwich Safeguarding Adults Board	Each Borough is required to set up a Board under Section 43 of the Care Act 2015, whose role is to oversee all Safeguarding Work in its area
SEG	Safeguarding Adults Evaluation Sub-group	A Sub Group of the RGSAB, whose role is to evaluate any cases which might require a statutory review, under Section 44 of the Care Act 2015
KPE	Key Practice Episode	Subdivisions of the full multi agency chronology, made by report author, to capture learning from interventions at significant periods of the case under Review.
ISC	Intermittent Self Catheterisation	Intermittent self-catheterisation (ISC), or clinically clean intermittent catheterisation (CCIC), is a long-accepted method of periodically draining a poorly emptying bladder. The patient or carer passes a catheter into the bladder to drain residual urine, helping to reduce infection and prevent the bladder from becoming over distended. https://www.nursinginpractice.com/intermittent-self-catheterisation

Appendix 2
List of Terminology used in the report

Terminology	Explanation	Reference
Septicaemia	Septicaemia occurs when a bacterial infection elsewhere in the body, such as the lungs or skin, enters the bloodstream. This is dangerous because the bacteria and their toxins can be carried through the bloodstream to your entire body. Septicaemia can quickly become life threatening. It must be treated in a hospital. If left untreated, septicaemia can progress to sepsis	https://www.healthline.com/health/septicemia
Pyelonephritis	Pyelonephritis —pus in the renal pelvis— results from urinary tract obstruction in the presence of pyelonephritis . Purulent exudate (inflammatory cells, infectious organisms, and necrotic, sloughed urothelium) collects in the hydronephrotic collecting system ("pus under pressure") and forms an abscess.	https://emedicine.medscape.com/article/440548-overview
Meningocele (Spina bifida)	Spina bifida is when a baby's spine and spinal cord don't develop properly in the womb, causing a gap in the spine. Spina bifida is a type of neural tube defect. The neural tube is the structure that eventually develops into the baby's brain and spinal cord. The neural tube starts to form in early pregnancy and closes about 4 weeks after conception. In Spina Bifida, part of the neural tube doesn't develop or close properly, leading to defects in the spinal cord and bones of the spine (vertebrae)	https://www.nhs.uk/conditions/spina-bifida/
Hydrocephalus	Hydrocephalus is a build-up of fluid in the brain. The excess fluid puts pressure on the brain, which can damage it. If left untreated, hydrocephalus can be fatal.	https://www.nhs.uk/conditions/hydrocephalus/
Myelomeningocele	Myelomeningocele is a birth defect in which the backbone and spinal canal do not close before birth. The condition is a type of Spina Bifida	https://medlineplus.gov/ency/article/001558.htm

Appendix 3

**Medical Report
on
'Mr F'
DOB. 19.02.1979
DOD: 06.03.2017**

**Prepared on the instructions of:
Royal Borough of Greenwich
Safeguarding Adults Board
35 Wellington Street
Woolwich
London SE18 6HQ
Ref: DX 400851 WOOLWICH 5**

**Report prepared by
Dr. D. J. Richard Morgan MB BS, FRCP.
Consultant Physician & Senior Lecturer in Medicine
Imperial College Faculty of Medicine
Chelsea & Westminster Hospital NHS Trust
London SW10 9NH**

14th February 2020

1. Introduction:

1. 1. This medical report has been prepared at the instruction of the Royal Borough of Greenwich Safeguarding Board regarding the care of 'Mr F' (deceased) formerly resident of the London Borough of Greenwich.
1. 2. In the preparation of this report I have had access to documents provided by the instructing Safeguarding Adults Board of the Royal Borough of Greenwich:
 - Integrated Chronology of the life of Mr F
 - Summary of Integrated Chronology of Mr F

2. Professional Qualifications & Appointments:

Qualifications:

- | | | |
|--------------------------------|-------------------------------|------|
| • MRCS LRCP | London | 1975 |
| • MB BS | London University (St. Barts) | 1975 |
| • MRCP (UK) | Royal College of Physicians | 1980 |
| • FRCP | RCP London | 1991 |
| • Diploma of Medical Education | University of Wales | 1997 |

2. 1. I am a Consultant Physician at the Chelsea & Westminster Hospital; appointed in 1988 and accredited as a Specialist in General Internal Medicine, Clinical Pharmacology and Therapeutics and Geriatric Medicine, on the Register of the General Medical Council (Registration Number: 2255187).
2. 2. I am an Honorary Senior Lecturer in Medicine at Imperial College Faculty of Medicine and was Chairman of the Imperial College Final MB BS. Board of Examiners 2002-8.
2. 3. I am also an Examiner for the Royal College of Physicians Membership Clinical Examinations since 2001.
2. 4. I was Clinical Director for the Medicine and Accident & Emergency Directorate of the Chelsea & Westminster Hospital NHS Foundation Trust 2002 -2014.
2. 5. Since 1990 I have been the Consultant in Charge of a specialist multi-disciplinary clinic for adults who were born with Spina bifida and/or Hydrocephalus. This specialist clinic provides annual and emergency follow up for patients with this complex congenital abnormality which causes variable neurological, mobility and continence problems for life. The service was established at the Chelsea & Westminster Hospital. Details of it were published in the Postgraduate Medical Journal 1995, volume 71, pages 17-21. We currently have over 500 patients under follow-up, age range of 16 to 84, with various levels of personal independence in daily living capability. This unique multi-disciplinary service has the largest cohort of adult Spina Bifida patients under follow-up in the United Kingdom.
2. 6. I am an Acute Medicine Physician, taking emergency medical referrals from General Practitioners, Emergency Department and secondary referrals from other consultant colleagues.

3. Professional Organisations:

I am a member of the following professional bodies and organisations:

- The British Medical Association
- The Royal Society for Medicine
- The Society for Acute Medicine
- The Society for Research into Spina Bifida & Hydrocephalus.
- British Geriatric Society

4. Mr F's health prior to March 2017 as recorded in his Integrated Chronology

4.1 Mr F was born with the congenital neural tube developmental abnormality called Spinal Dysraphism, commonly referred to as Spina Bifida. This condition often results in significant disability affecting many aspects of an individual's development and subsequent health. This includes:

- Mobility problems due to neurological disorder of motor and sensory input to the limbs especially the lower limbs.
- Cognitive and emotional development problems, especially when hydrocephalus is present and even when shunted.
- Neurogenic bladder and bowel incontinence.
- Pressure ulcer development due to absent sensation in legs and saddle area
- Obesity and related medical conditions due to immobility which reduces exertional activity as patients become older. This includes Respiratory failure partly from chest deformity and due to central respiratory centre depression from the later effects of treated hydrocephalus.
- Psycho-social related difficulties related to disability, limited employment opportunities, prejudice and discrimination, social isolation and access to healthcare resource provision problems.

4.2. Mr F's Spina Bifida was apparent at birth with a visible lumbar myelomeningocele. This was repaired on the first week of life at the Sydenham Children's Hospital, Lewisham. . Mr F then moved away to live in Hull during his childhood. During this time, he developed divergent squint and had ophthalmic surgery to correct this. Squint is a common feature of hydrocephalus related problems. Pallor of the optic discs was observed – which suggests optic nerve atrophy following raised intra-cerebral pressure, because of unrelieved hydrocephalus. It also results in visual impairment and reduced acuity. At some stage Mr F was diagnosed with hydrocephalus which was managed by shunt insertion. This was complicated by several insertions/reconnections. He never had any epileptiform events. Intellectually he attended special schooling, and apparently did not achieve any secondary Examinations. He did not ever manage to have any employment.

4.3. Mr F had problems with of both legs from infancy. This resulted in walking difficulty and the need for special shoes. There is no detail of any corrective orthopaedic surgery. In 2007 Mr F (now aged 28) returned to London with his father, following the death of his mother. Foot ulceration was present and managed by dressings in the community. He walked with the use of frames, tea trolleys, or wheelchairs latterly. He tended to crawl about at home and developed callouses on his knees as a result.

4.4. Mr F had multiple foot problems characteristic of a paraplegic patient:

- Pressure ulcers – 2007/8 – right foot – seen at QEH Woolwich. Osteomyelitis suspected.
 - Recurrent cellulitis occurred in 2007 requiring repeated antibiotics and regular dressings and wound cleaning by district nurses of attendance at clinics.
 - Leg swelling and colour change from lymphoedema – often suspected as vascular disease but normal arterial flow seen.
 - Chronic low back pain
 - Mobility difficulty – wheelchair assessment and provision
 - Special shoe provisions
 - Bathing facilities – access to shower/bath or wet room.
 - Further episodes of foot infection 2009-2012 with orthopaedic and podiatry follow-up after acute illness with non-attendance at review appointments, and some community care.
- 4.5. Bladder & Bowel continence is often a problem for Spina Bifida patients. Mr F had urinary spontaneous voiding and was taught Intermittent Self Catheterisation (ISC) which appears to have been reasonably successful. Mr F had intermittent urinary tract infections managed with antibiotics as required.
- 4.6. Bowel continence had been satisfactory in childhood and manageable with a healthy high fibre diet. In 2008 Mr F had episodes of soiling and incontinence requiring a pad for protection ever since.
- 4.7. In 2008 Mr F was referred to the Neurology clinic for review because of intermittent headaches. The letter from the consultant stated that Mr F had not had any review for some time. There were also symptoms of shortness of breath, weight gain, poor mobility. Headaches were not indicative of pressure effects. No examination findings are recorded. CT brain scan was arranged and subsequently reported as showing large ventricles with the shunt position 'okay'. Six monthly follow-up advised, but attendance was poor with frequent cancellations by Mr F over subsequent years.
- 4.9. Socially in 2008 Mr F lived with his Father in a house with steep step access and railings to aid Mr F which had poor wheelchair access. It was described as a residential location. Application for independent rented local authority accommodations to allow him independent living separate from his father who now had a new relationship. He was a smoker. Father drives a Motability car and drives Mr F about as needed. Mr F received high rate DLA benefits on account of his disability. He attends a local pub for social activity to watch football with friends. He declined offers of social care for shopping and personal care.

5. 2012 to 2017 and subsequent events.

- 5.1. Mr F moved to independent living in a purpose built flat fully adapted for wheelchair user with gated access. His attendance at healthcare appointments became almost non-existent. GP services provided repeat prescriptions for urinary catheters for ISC.
- 5.2. Home visit assessment by Occupational therapist in June 2012 recorded significant weight gain of approximately 3 stones to 16 stone and a height of 4 foot 10 inches

(BMI of 47 – morbid obesity). At risk behaviour was recorded, falls risks and transfer risks were seen. MR F declined offers of help.

- 5.3. Apparently thereafter for approximately four years Mr F was not seen or assessed by any healthcare or social professional. Applications for Benefits renewals were made on his behalf also without being seen.
- 5.4. On Friday 3rd March 2017 Mr F's Father visited him to ' help him sort out his flat', but Mr F refused to allow his father to come in. His father was concerned that Mr F looked unwell, and apparently advised Mr F to go to hospital, but this was refused. His father said he would return after the weekend.
- 5.5. On Monday 6th March 2017, Mr F's father found Mr F dead lying on the floor of the flat with Rigor Mortis present. Mr F was unclothed from the waist down, and his lower body covered with faeces. His right knee was ulcerated through to the knee joint. The right foot was also infected and swollen.
- 5.6. The results of the Coroner's Inquest was that the Cause of Death of Mr F was:
 - 1a. Septicaemia
 - 1b. Pyelonephritis
 - 1c. Ascending Urinary Tract Infection.
 11. Infected Leg Ulcer.

6. Opinion:

- 6.1. Mr F was a patient with Spina Bifida & Hydrocephalus, neurogenic bladder and bowel with paraplegia. He had addition significant co-morbidities of morbid obesity and lymphoedema with leg ulcers at the time of his death from Septicaemia due to urinary tract infection and leg ulceration.
- 6.2. His care during the last five years of his life from medical and local authority social care services appears to have been minimum, in part due to Mr F's own wishes and refusal to attend follow-up appointments. This lack of regular assessment by community and secondary health care services was responsible for the development of severe complications which caused his collapse at home. Inadequate regular review of the urinary tract by consistent medical assessment and investigations failed to identify the significant potential for sepsis which could have been prevented. Patients with spina bifida and neurogenic bladders are known to be at high risk of urinary tract sepsis and because of immobility and lack of sensory neurological function they do not feel symptoms in the same way as 'normal' patients. This should have been identified as a high risk of sepsis being present on the General Practice and community records. Patients with neurogenic bladder who are performing ISC should be reviewed annually, with urine culture, blood renal function tests and renal tract imaging – usually by ultrasound with pre and post micturition bladder volumes measured. Most patients attend a local urology service, often nurse lead for this annual review.
- 6.3. There are no records of Mr F's respiratory function prior to this illness. However, his hydrocephalus and obesity are likely predisposing conditions which often result in mid-life respiratory failure in spina bifida patients. Obstructive sleep apnoea requiring NIV (Nocturnal Intermittent Ventilation) is not uncommon in our cohort of patients. This can

contribute to fatigue, somnolence, depression and inertia which is insidious in onset. Mr F complained of shortness of breath in 2012, which was never fully evaluated. I consider it likely that Mr F would have developed compromised Respiratory function, probably requiring home NIV therapy within ten years even without his eventual collapse and death in 2017.

- 6.4. It should be noted that many 'older' patients with Spina bifida become less mobile with time, even if they were ambulant formerly. This is due to a combination of factors. Degenerative spinal disease is a major factor. The developmental deficiency in the spinal architecture makes for premature osteoarthritic complications. When a patient is overweight this compounds their situation. 90% of patients with spina bifida are overweight. Mr F had morbid obesity (BMI >40) and it is probable that he would have become electric wheel-chair dependant within a few years. This mechanical disadvantage also caused extra strain on the upper limb girdles and forearms, with tendonitis, rotator cuff injury and osteoarthritic complications in the shoulder joints appearing in the fifth and sixth decades. Many spina bifida patients living alone (especially men) tend to live off convenience foods such as take-aways and ready prepared micro-wave able meals. Dietitian input can help, and weight losing support services also beneficial. Morbid obesity patients should be considered for gastric by-pass surgery and monitored for the development of diabetes. Patients who are house-bound and eating poor diets are frequently vitamin deficient which increases risk of ill health (fractures/osteomalacia from vitamin D deficiency, low folate and iron levels causes poor wound healing).
- 6.5. Neurologically Mr F had been assessed in 2012, and Brain Imaging in the form of a CT Brain scan had shown chronic megacephaly (Enlarged lateral ventricles within the Cerebral cortex) with a normally placed shunt. The headaches he complained of were considered not to be due to raised intracranial pressure, or shunt malfunction. No cognitive evaluation was recorded. There is no detail of Mr F's academic achievements as a young man/child. It is not clear whether any attempts were made to find any occupation or voluntary activities for him in his adult life. His main support and carer were his father who clearly maintained a significant degree of involvement in Mr F's care even when he moved out of the Father's house in 2012.
- 6.6. Hydrocephalus causes long-term cognitive impairment. We have published scientific work evaluating patients' capabilities in cognitive neuro-psychological testing. Even with preserved IQ and normal cognitive screening (MMSE and AMTS) there are often significant impairment in functional executive performance. This deficit may manifest in poor decision making, impaired short-term recall and inappropriate behaviour. Resulting mental health problems can then become apparent with anxiety and depression frequently developing. These features are all compounded by social isolation.
- 6.5. There was a clear deterioration in mobility as a result of Mr F's move into independent living, despite having a flat with modifications to accommodate his disability. This was undoubtedly brought about by the circumstances of his community care. If Mr F had engaged with regular care review of his medical and social health, with respect for his autonomy but consideration for his disability both physical and cognitive, providing a consistent supervision it is my opinion that this deterioration would have been avoided.

- 6.6. He should have received community care and physical reviews of his various medical system conditions -urological, neurological, orthopaedic/podiatry and district nursing for his leg swelling (lymphoedema) and ulceration. Specialist nursing input from a Continence Nursing and Tissue Viability should have been involved, and appliance/orthotic services and the local wheelchair clinic regular assessment provided. Problems such as possible osteomyelitis of the bones in the feet when ulceration occurs require multi-specialty cooperation, vascular surgeons, orthopaedic surgeons, plastic surgeons and microbiology, as well as appropriate imaging. MRI scanning provides the best investigations, and plain x-rays only show destruction relatively late.
- 6.7. Ideally this care plan would be provided in a multi-disciplinary clinic situation, maximising the expertise of various specialists both medical/surgical and nursing and therapy (physiotherapy and occupational therapy) with social services input in a whole day annual review with appropriate investigations arranged to occur on the same day. This would have ensured that effective investigations happened and decisions about his care were agreed, and not frustrated by his non-attendance.
- 6.8. Medical services in hospitals today are pressurised into maximising efficiency of outpatient management, and inpatient admissions are increasingly restricted to emergency issues, with the imperative to discharge patients to the community as soon as possible. Admissions for prolonged treatment for infected leg ulceration or pressure ulcers are infrequent, and continuity of care is limited. Many clinicians fail to appreciate the effort and difficulty it requires for a patient with mobility difficulties to attend for outpatient clinics. One nonattendance results in discharge from the system. I note that one such event happened when Mr F was an inpatient as an emergency and could not come to clinic. This is a failure by the hospital medical services to recognise the difficulties of disabled people with long-term neurological conditions such as Spina Bifida & Hydrocephalus, as was the case for Mr F. It then falls to their carers or General Practitioner or Social Services to pursue their care, as the patient often feels neglected, and that that they do not see any benefit from the attendance in hospital. Improving their health situation requires persistence, encouragement, flexibility and developing a relationship with the individual.

7. Specific responses to Questions from instructing party.

- 7.1. How did Mr F's specific medical conditions of Spina Bifida & Hydrocephalus contribute to or affect his decision making and insight into the nature of his health and care needs?

Hydrocephalus even when decompressed and treated with a shunt causes variable intellectual compromise. This manifests with short-term memory recall difficulty, and executive functioning problems. Some patients have a frontal lobe syndrome with a degree of 'belle indifference' attitude, which may result in them declining offers of assistance or attending clinical follow-up in the hospital or community. Patients with hydrocephalus may appear mentally competent but can be overconfident about their ability to manage their health care needs until a crisis develops. I note that Mr F was described as very articulate by a community OT in 2007, and elsewhere that he had some memory difficulty, but it was not a problem. This was true when he lived with his father who as his fulltime carer provided Mr F with comprehensive support, and with the authority and love of a parent could cajole Mr F into complying with much of his essential needs and medical care. Once Mr F moved away from his father into

independent living, this supervision was lost and a downward spiral in health and social care begun.

A second factor related to the Spina Bifida effect on Mr F's response to illness is that patients with spinal injury are insensitive to pain below the level of the spinal damage. This means they do not feel the pain of injury or inflammation in their extremities, and infection becomes established with systemic effect before it is realised that they are ill. This may be from skin infections, pressure ulcers, trauma from poorly fitting shoes/appliances, burns from hot water/bottles/proximity to fires etc, and from internal infections such as urinary tract infections. Patients can fracture bones without experiencing pain, and minor trauma (banging legs when going through doors) may result in significant injury. It is also often surprising that medical staff and nurses are not aware of this lack of sensation and its implications for the healthcare of spina bifida patients.

7.2. What should the recommended care be for patients such as Mr F with long term neurological conditions by primary and Secondary care services?

Patients such as Mr F often find that when they reach the age of 16 to 18, and are discharged from children's services that there is no regular medical follow-up, and that they are left to the General Practitioner services, who are not resourced or trained to manage such complex medical and social problems. This then results in crisis management, and referrals to different separate adult system referrals as and when the need arises. This causes a loss of trust by the patient in the care agencies that anyone is concerned about them as an individual.

Ideally care should be multi-disciplinary and multi-specialty, preferably in combined clinics in secondary setting, with pre-planned appropriate investigations. The service should be led by a 'holistic' lead who can provide an overall view and continuity for the patient and his/her community healthcare and social services. Each patient will have priorities, but urology services and continence services for bowel and urine management is a main priority. Neurology expertise is also important, as many spina bifida patients have hydrocephalus, epilepsy, and learning difficulties. Access to neuropsychology for cognitive evaluation is a useful extra. Therapy expertise from a neuro or musculo-skeletal physiotherapist and a community based occupational therapist will provide invaluable assessment of ADL (Activities of Daily Living) capability. A specialist in Daily Living needs – charity supported or from social services to discuss benefit needs, help with PIP application, independence living opportunities, and to help with employment issues is very helpful. Good secretarial support with telephone/email access to provide contact with patients/carers/fellow professionals for enquiries and appointment arrangements and to deal with concerns between appointments is essential for the service to be effective and efficient, as well as reassuring for patients.

In reality such a situation is only available at Chelsea & Westminster Hospital for Adults, although some Regional Neuro-rehabilitation services such as Oxford Nuffield Hospital is providing a service. Most hospitals will not run such a service, although some System based specialties (Urology and Orthopaedics) have special monthly spina bifida clinics, with therapists and expertise focussed on a particular need. There is a need for multi-agency specialty clinics for neuro-degenerative conditions, with nursing and medical as well as social/therapy input to regularly review such clients and to provide a regular 'MOT' check on the broad aspects of healthcare for such patients.

Such services can prevent deterioration and reduce acute admissions with crisis problems. However, the present contracting processes in the NHS seem not to be in favour of such an approach.

- 7.3. What should have been the suitable treatment/care plan for Mr F, particularly given he received repeat prescriptions for urinary catheters without any apparent health review?

Any patient receiving continued repeat prescriptions should be reviewed six to twelve monthly to assess the appropriateness of the treatment. Mr F's need for catheters was essential and it would be wrong not to continue to supply his need just because of non-engagement with healthcare. However, it should have been possible for someone (GP, District Nursing services, Local Continence Nursing Advisor, Urology services) to make Mr F or his carer/father to engage for review, and appropriate checks – urine samples for infection, blood tests of renal function and general health at least annually even if asymptomatic, and renal tract imaging to look for obstruction and stones which can result in renal failure. Continence management would improve his self-esteem, and encourage him to engage with socialising, and improve his mood.

Regarding his legs – monitoring for ulceration, and management of lymphoedema by compression hosiery, or other measures such as appliances for his feet such as splints/AFOs (Ankle Foot Orthoses) and specialist shoe provisions would make him feel more 'normal' and enable him to go out more. Three to six monthly domiciliary community podiatry was also required. Regular wheelchair clinic review and chair cushion assessment to ensure that sacral pressure ulcers do not develop.

That would have been the minimum healthcare involvement that should have been in place. If that had been achieved, and professionals not been put off by Mr F's non engagement or cancelling of appointments, his progressive deterioration and ultimate death may have been prevented.

- 7.4. Please give your opinion on any impact Mr F's medical conditions could have on cognitive functioning, in particularly his ability to manage access and engage with relevant medical professionals and/or care and support plans/treatment regimes.

Mr F should have been identified as a person with probable impaired intellect from hydrocephalus, and his cognitive function properly evaluated, and mental capacity formerly assessed. He was a person likely to be vulnerable and as such have safeguarding processes in place and ongoing. His ability to manage his personal health after leaving his father's house to live independently was probably inadequate. As mentioned above in 7.1. Hydrocephalus even after successful shunting causes variable degrees of cognitive impairment, and memory difficulty, and often causes frontal lobe injury which may result in behavioural difficulty. Patients become passive, and apathetic, uncomplaining and reluctant to engage with family, carers and medical professionals. Refusal to attend for health care management should not be left unchallenged or accepted as personal autonomy choice without question and considered for reassessment, involving a responsible next of kin or IMCA.

- 7.5. Any other comments.

Life expectancy in patients with Spina Bifida and neurogenic bladder is dependent upon the care and supervision the patient receives, and the degree to which he/she complies with medical advice. Spina Bifida patients have a reduced life expectancy,

and obesity, pressure ulcers/skin infections also reduce life expectancy. Mr F had a slow decline with lesser level of mobility and quality of life following the move to independent living. Without reviews he was vulnerable to a variety of potential complications which affected his life expectancy significantly.

8. Conclusion:

- 8.1. Mr F collapsed due to septic shock probably from urosepsis. Failure to provide regular medical and social care review for the last five years of his life probably contributed to his deterioration and development of serious pressure ulcers which was preventable with an appropriate care plan and implementation.
- 8.2. Mr F's congenital condition of Spina Bifida was of a moderate degree, and having survived childhood, his long-term survival was dependent upon his medical, psychological and social support, relating to the problems of neurogenic bladder and bowel continence, paraplegia and pressure ulcer prevention. Hydrocephalus contributed to his cognitive functioning and was probably responsible in part for his nonattendance with medical follow-up after his move to independent living. The severe obesity also contributed to his health problems.
- 9.3. His general quality of life and long-term prognosis was probably influenced by the lack of medical or healthcare involvement for the last five years of his life.

Statement of truth:

I confirm I have made clear which facts and matters referred to in this report are within my own knowledge and which are not. Those that are within my knowledge I confirm to be true. The opinions I have expressed represent my true and complete professional opinions on the matters to which they refer.



Signature:

Date: 15th February 2020

DR. D. J. R. MORGAN. MB BS, FRCP.
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