

THE FINDLAY REPORT

Case study on the handling of Motor Neurone Disease by UK health and social services

This case study is an analysis of the treatment received by our father, James Findlay, just prior to confirmation that he had motor neurone disease (confirmed on 25 October 2005 by MND specialist) up until his death on 30 December 2005.

It has been written by members of his family who were directly involved with his care over a four month period.

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Foreword

“Whatever you do, don’t get this bloody awful disease”

- David Niven, actor and sufferer of Motor Neurone Disease

That’s what the actor David Niven thought about it when he was diagnosed with Motor Neurone Disease (referred to as MND through this report) about 25 years ago. It claimed his life in 1983. Twenty-two years after this happened, our father and us, his family, would come to concur with his sentiment.

Motor Neurone Disease is a cruel and unforgiving condition that can strike someone at any age. Unlike some other progressive conditions, it offers no remission or much hope of some ‘good’ days in-between the ‘bad’ ones. It’s relentless with no known cure and not a lot of knowledge about how or why it strikes. For these reasons, the way it is treated by health and social services professionals is of paramount importance – to the person concerned who has to deal with it and to their family who have to help them deal with it.

All the family knew when our father was diagnosed with the condition in October 2005 was that this was what David Niven had. We all hit the internet to find out more. The internet was to be the major source of the family’s information about the disease and its treatments for two months. We were even feeding information about it to various health professionals, as their knowledge proved to be patchy or non-existent.

There are inevitably a lot of concerns expressed in this report about the treatment that our father received. It does not pull its punches. But it is not intended to be merely a litany of whingeing and complaints. They help to set the scene and the background that leads on to our thought out and constructive recommendations to the health and social services in this country to assist in plans for the future treatment and handling of people diagnosed with this “bloody awful condition.”

It is the family’s attempt to communicate constructively with the health and social services professionals who sought to deal with our father’s condition – and who did so with varying degrees of usefulness, compassion and understanding. We only wish those same professionals had sought to communicate with us and between themselves in a similar manner.

The family believes that the recommendations and conclusions contained in this report are applicable across the health and social services nationally – not just confined to our father’s case or just to one area.

Introduction

This report is presented in three parts:

- following this foreword, main threads and recommendations are set out;
- then an executive summary of the main recommendations for ease of reading;
- some final concluding remarks and communications diagrams;
- and then a chronology of events based on a day-by-day diary compiled by my father's family over the four months of the treatment and handling he received from health and social services prior to and during his illness - and the role the family had to play. It covers the period from September to December 2005 inclusive.

It also includes details about the treatment our mother was receiving during this time. She is important, as our father had been her main carer at home for some years. She had had a stroke about eight years previously that developed into dementia. How she was doing was important to him – if she was okay, he was okay. They had been married for 62 years.

As far as the family was concerned, this made her a vital part of our father's overall care package and helps explain why the family took some of the actions and decisions that it did. It also helps explain why the family believes a holistic approach to the treatment of someone with MND and other neurological conditions is crucial.

Main threads with recommendations

1) Making a diagnosis

The chronology of events helps in the process of pulling out the main threads of problems the family encountered as the disease progressed. The first problem came with diagnosis. We came to learn that MND is not easy to diagnose – it's only when symptoms become more pronounced that it can be confirmed eg slurring of voice due to bulbar palsy.

Family and friends noticed that James's voice was croaky in July 2005. This was variously put down to sore throat; flu; cold coming on etc. James had been tested for Parkinson's disease some time earlier as he had been shaking a lot and having difficulty in holding a cup of tea without spilling it. Parkinson's was eliminated and his condition was put down to age. No further tests were made.

Recommendation one

That motor neurone disease is added to the list of diseases, along with multiple sclerosis, muscular dystrophy, brain tumour and Parkinson's that tests can be made for in the early process of elimination.

Early diagnosis is so vital with MND. That's why there needs to be more creative thought, imagination and lateral thinking applied to methods employed to detect it. Even a suspicion of it by a GP would mean they could keep a regular check on the individual and could bring in assistance from the individual's family to also keep an eye on how symptoms progress – even suggesting that a diary of symptoms is kept and fed back regularly to the GP would be extremely useful.

A national standard procedure could be set up for this kind of involvement between the individual, family and GP. It's so important to set wheels in motion once there are strong indications that it could be MND because, as we discovered, it can be unpredictable, aggressive and progress extremely quickly.

Recommendation two

Set up national standard guidelines and templates aimed at General Practitioners, for use in conjunction with individuals being treated and their families, to promote active co-operation between a family and GP in order to assist the process of diagnosing hard to detect degenerative and progressive conditions such as MND. This should also be used in conjunction with social services where appropriate. For example, if the individual being treated is receiving help from social services and has a care manager.

2) Once diagnosis is confirmed

It's really not good enough, as happened with James, for a hospital to rely on written information about MND aimed at a patient to be solely provided by the MND Association, good though this organisation may be. It is a voluntary body. The specialist consultant should provide written information to back up everything that he or she is telling the individual concerned and given to the person at the time. James came away from both sessions with his consultant with no written information whatsoever – he and the family with him were expected to remember it all in spite of being in some shock in trying just to cope with the implications of the diagnosis.

It was also clear that the consultant had not properly explained, or made sure that James fully understood, the implications of the disease as it would affect his life. James really thought the pills he was prescribed – Rilutek – would cure him.

Recommendation three

Once diagnosed, as much information as possible should be supplied to the individual concerned – if it's thought they can deal with it – but most certainly to their family. This information should be available possibly from the GP but most certainly from the consultant and should be in a digestible form.

It should include details about the possible development of the disease; explanations about the different types (four types of MND); what the family should look out for as the disease progresses and be provided with a template for plotting the development of the disease.

It was surprising that my father's consultant did not appear to benchmark his condition at the first consultation he had with him. How could he then measure the deterioration at the second consultation two weeks later if he had no benchmarks to go by? It would have been even more obvious that James had deteriorated in those weeks. If the family had been keeping a day-by-day diary of his decline, in conjunction with his GP, this information could have been provided to the consultant - all of this would have indicated just how quickly James's condition was progressing. This should then have set alarm bells ringing and a new plan put into action immediately. However, without this kind of information, the consultant acted as though James had some months left to live when he saw him the second time. He even set the appointment for his third consultation as 11 January 2006 – two months ahead. Another question is why the consultant didn't refer James back to the hospital nearer his home as soon as diagnosis was confirmed as he must have known how difficult it would be for James to travel any great distance.

Recommendation four

National guidelines should be provided for all consultants concerned with diagnosing and treating MND outlining what should happen when they have confirmed a diagnosis of MND, including details of the benchmarks they have to use to measure the progress of the disease; the regularity by which they have to benchmark the patient; what to do when certain criteria emerge eg from slurring of speech to loss of voice and time between these two events which may well help indicate the rapidity of the disease. This leads on to the next, and crucial, recommendation.

Recommendation five

Once diagnosis has been confirmed, the very first task is for a co-ordinator, conductor, project manager – call it what you will – to be appointed. This could be a health or social services person, or someone independent but proficient in project management. This person takes charge of the case and covers the whole range of the patient's needs – a holistic approach. This conductor is absolutely critical in pulling together all the various agencies and people who will be involved with the patient's treatment over the coming weeks/months/years covering health, social services and others. They will also look at the patient's living conditions; relationships; co-ordinate the family's input into the process. They will ensure effective communication between different professionals involved with the case. They will be on hand to ring alarm bells if the condition is moving on quickly, triggering necessary action eg quick assessment from a hospice consultant. They will be able to work with the patient and family in the home; during any stays in hospital; any stays in a nursing home. They should have their authority recognised by all the professional practitioners involved with the case and their observations/recommendations taken into account. They should act like a conductor of an orchestra making sure all the instruments are present and bringing them in according to a plan as and when necessary, to ensure harmonies are struck and to provide synergy. Someone who can deal with bureaucratic ineptitude within and between health and social services authorities eg in James's case, faxes kept going missing between two Health Authorities which meant breathing equipment never arrived at his GP's surgery – never did, as far as we are aware. This also applies to a lightwriter when the family was told repeatedly that it had been ordered when it hadn't been. Delays caused by inept administration. The family has a crucial role to play in this, alongside the 'conductor.'

Recommendation six

That the family be regarded by all the health and social professionals involved as 'part of the team' and treated accordingly. The consultant and his/her team should be gathering information about the family circumstances and not making assumptions, as seemed to happen in our father's case. No account was taken by his consultant of his home situation. He seemed to think that his daughter was his carer which wasn't the case. James was himself a carer so the diagnosis was not only going to affect his life in a dramatic way but also that of the person he was caring for. This should have been taken into account at an early stage of diagnosis as it would obviously impact on James's emotional and mental ability to cope with his MND.

3) Further next steps

Communication

It takes an experience like coping with a progressive and degenerative condition such as motor neurone disease, either yourself or a family member, to realise just how bad communication is between those bodies and individuals who are supposed to be providing treatment and care.

Just reading through the chronology of events it becomes self-evident that there was an appalling lack of communication between all the professionals involved on the health side and between health and social services. It should be said that the input James and the family received from local social services was light years in advance of the health services in its understanding and speed of action.

On the health side, however – it's another story. For example - James was seen by a neurological consultant at his local hospital, having been referred there by his GP. This consultant could see the urgency of James's condition and referred him to a specialist in MND based at another hospital some distance away. Problem – the first consultant said that administrative tasks ie movement of paperwork backwards and forwards between the two Health Authorities involved were experiencing hold-ups of at least a fortnight. So, the first consultant got in his car with James's paperwork, drove to the other hospital and handed the notes personally to the specialist consultant.

Problem - the family was told that James would need an MRI scan that could take up to a month to organise and he would need it before he could see the specialist. It is known that MND can be a very rapid and aggressive condition – although neither James nor his family were ever warned about just how quick it could progress at the time – so how could the hospital possibly think that a delay of a month was acceptable?

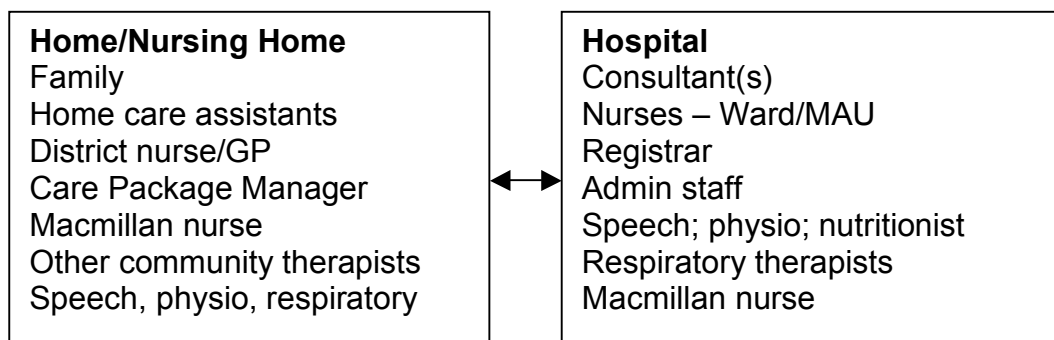
Recommendation seven

The two Health Authorities need to sort it out. They must improve their communications methods with each other. In this technological age, there's no excuse.

The communications and co-ordination between those caring for James at home and those in the hospital seemed non-existent. It appeared that notes and assessments from those involved when James was at home, or in the nursing home, were not passed on to the hospital equivalents. Valuable time was wasted re-assessing James's condition – particularly in the Medical Assessment Unit (MAU) at the hospital when he was admitted for a peg feed operation.

The lack of appropriate treatment that James had to endure while in the MAU, and to begin with in the general ward, makes for grim reading in the chronology of events. It's not something that pumping money in can solve – it's a question of basic nursing standards and care being adhered to. Some of the nurses and admin staff need to question whether they are in the right profession and the hospital hierarchy need to examine whether they have the right kind of staff in place. There was a general lack of leadership on display – something for the hospital hierarchy to get to grips with as well. They should also consider training their staff – medical and admin – on the skills of communication with relatives and how to handle patients so they can maintain their dignity. One of the registrars on duty at the time, and some of the nursing staff, agreed that basic nursing standards were not being met throughout James's stay in the hospital. There was a lack of knowledge about motor neurone disease among the medical staff there that led to some of them handling James in a completely inappropriate manner and could have had very serious consequences for him.

The following diagram shows those that were involved in James's care at home and in hospital:



No communication
No co-ordination

Executive summary of recommendations

1. That motor neurone disease is added to the list of diseases, along with multiple sclerosis, muscular dystrophy, brain tumour and Parkinson's, that tests can be made for in the early process of elimination.
2. Set up national standard guidelines and templates aimed at General Practitioners to assist the process of diagnosing hard to detect degenerative and progressive conditions such as MND.
3. Once diagnosed, as much information as possible should be supplied to the individual concerned and to their family. This information should be available possibly from the GP but most certainly from the consultant.
4. National guidelines should be provided for all consultants concerned with diagnosing and treating MND outlining what should happen when they have confirmed a diagnosis of MND, including details of the benchmarks they have to use to measure the progress of the disease with input from family members as appropriate.
5. Once diagnosis has been confirmed, the very first task is for a co-ordinator, conductor, project manager to be appointed. This person takes charge of the case and covers the whole range of the patient's needs taking a holistic approach. This conductor is absolutely critical in pulling together all the various agencies and people who will be involved with the patient's treatment over the coming weeks/months/years covering health, social services and other areas.
6. That the family be regarded by all the health and social professionals involved as 'part of the team' and treated accordingly.
7. The two adjoining Health Authorities to sort out and improve the efficiency of their communications practices and procedures with each other.

Concluding comments

There are other areas that also concerned the Findlay family that have not been touched upon in this report but are important. They may form the subject of a separate report. For instance, an area that needs more thought is the medication that is prescribed for Motor Neurone Disease. Rilutek in tablet form was almost of no use at all to James as he had great difficulty in swallowing it. He spent three hours one afternoon trying to swallow a tablet – he genuinely thought it would cure him so he made the effort. More research needs to be carried out into how this drug, and any future drugs, can be given in an appropriate form, where difficulty in swallowing is part of the condition. How about in thick liquid form or even a patch?

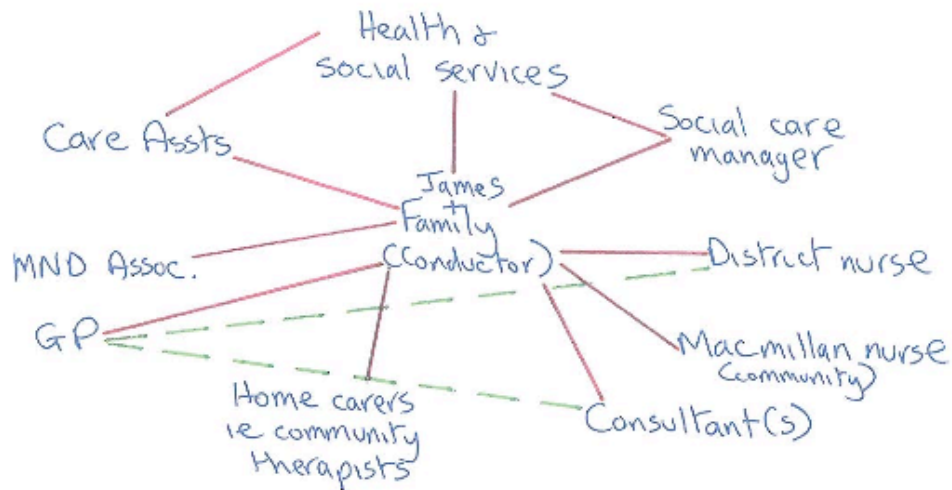
We commend this report to you.

COMMUNICATIONS DIAGRAMS 1 and 2

To illustrate how communication processes didn't work and could have worked better, two sets of communications diagrams have been devised.

Diagram 1

(a) What happened: home/nursing home



(b) What could happen: home/nursing home

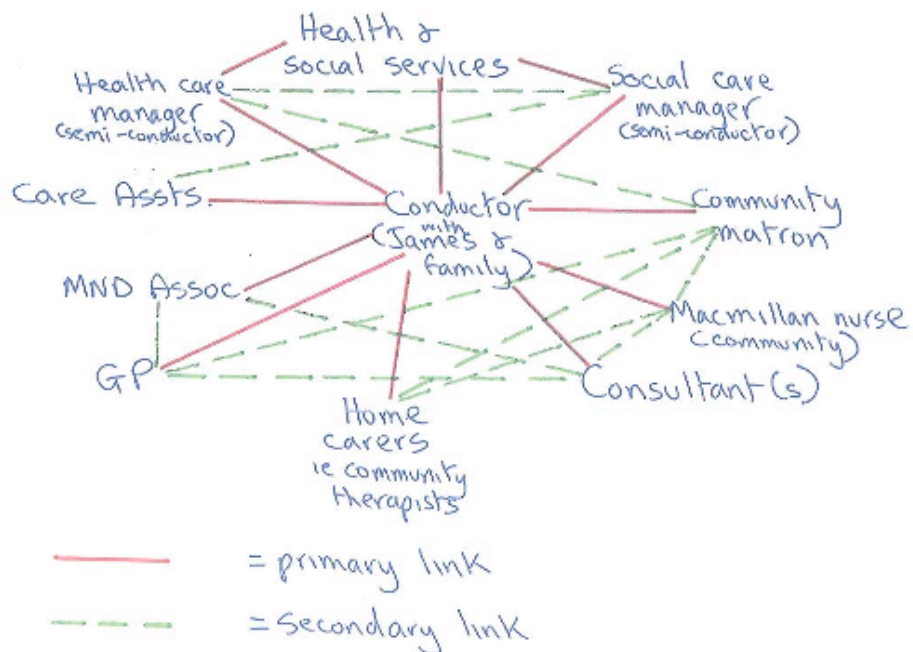


Diagram 1

(a) What happened: Home/Nursing Home

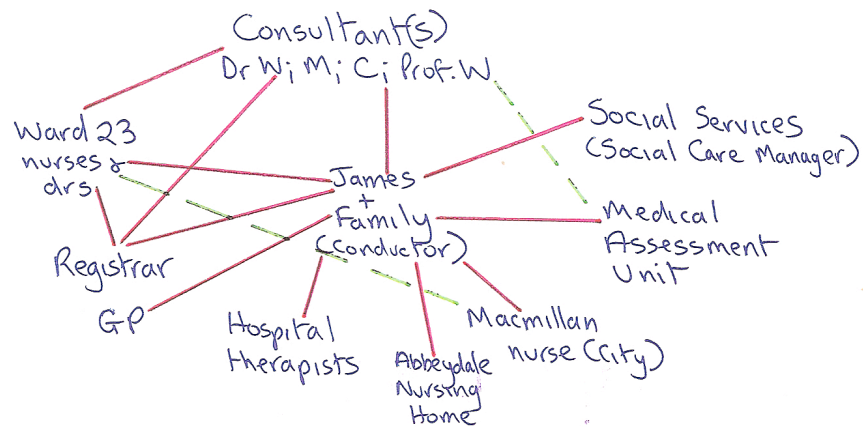
This diagram illustrates how the lines of co-ordination and communication operated between those charged with caring for James and between him and his family while he was in his own home. It shows clearly how the family was at the centre but had to play the role of conductor instead of a purely nurturing and supportive role for James.

(b) What could happen: Home/Nursing Home

This diagram illustrates how the lines of co-ordination and communication could have operated between the professionals charged with James's care while he was in his own home. The family and James still at the centre, but instead of playing the role of conductor, they would have a separate conductor working alongside and with them co-ordinating with professionals.

Diagram 2.

(a) What happened : hospital



(b) What could happen : hospital

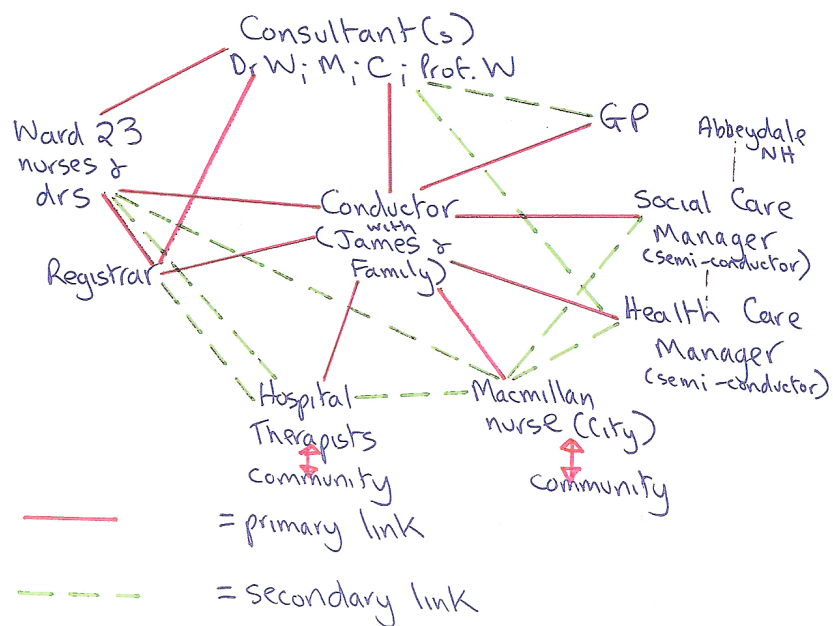


Diagram 2

(a) What happened: Hospital

This diagram illustrates how the lines of co-ordination and communication operated between those charged with caring for James and between him and his family while he was in hospital. It shows clearly again how James and particularly his family were at the centre, having to play the role of conductor for his care instead of a supportive role for him.

(b) What could happen: Hospital

This diagram illustrates how the lines of co-ordination and communication could have operated between those charged with James's care while he was in hospital. The family and James at the centre, but the conductor (the same person that played this role while he was in his own home) taking overall control alongside James and his family and making sure the professionals were co-ordinated and contacted/arrived at appropriate times.

THE FINDLAY REPORT (2)

DAY BY DAY CHRONOLOGY OF EVENTS COVERING FOUR MONTHS LEADING UP TO AND FOLLOWING OUR FATHER, JAMES'S DIAGNOSIS OF MOTOR NEURONE DISEASE IN OCTOBER 2005 (compiled by his family)

Sept 1 Thu

A family member visited/contacted mum and dad every day from this date onwards

Sept 2 Fri

Sept 3 Sat

Sept 4 Sun

Sept 5 Mon

GP visited dad. Suggested a blood test.

Sept 6 Tue

Sept 7 Wed

Sept 8 Thu

Sept 9 Fri

Sept 10 Sat

Sept 11 Sun

Sept 12 Mon

Sept 13 Tue

Sept 14 Wed

Sept 15 Thu

Sept 16 Fri

A District Nurse visited dad to take a blood sample. What did the blood test show?

Sept 17 Sat

Sept 18 Sun

Sept 19 Mon

Sept 20 Tue

Sept 21 Wed

Sept 22 Thu

Sept 23 Fri

Sept 24 Sat

Sept 25 Sun

Sept 26 Mon

Sept 27 Tue

Sept 28 Wed

Sept 29 Thu

Sept 30 Fri

A District Nurse visited dad to take a blood sample. What did the blood test show?

Oct 1 Sat

Oct 2 Sun

Oct 3 Mon

Oct 4 Tue

GP visited dad. Urgently referred him to the local acute hospital. Thought it might be a brain tumour

Oct 5 Wed

Oct 6 Thu

Oct 7 Fri

Oct 8 Sat

Oct 9 Sun

Oct 10 Mon

Oct 11 Tue

Early morning about 5am, mum fallen; dad came out to help and fell over her stick. Cracked his head open – blood everywhere. Tried to cope himself; daughter arrived about 11am and took mum to hairdresser (she couldn't be left on her own) and dad to doctor. Seen by nurse who cleaned him up and dressed wound on back of his head – didn't need stitches.

Oct 12 Wed

Oct 13 Thu

Oct 14 Fri

Dad saw first consultant at local hospital – daughter had to help him undress because so weak. Dr said 'he's not a well man.' He thought it was to do with nerve endings. Would refer dad for scan and urgent referral to specialist at another hospital & said it could take two weeks for referral to happen and a scan up to a month. Family asked if really have to wait this long and Dr said terrible, long communications blocks between the two health authorities. Dr got in car and took dad's notes personally to specialist at other hospital because of backlog. Family hit the phones to try and book a scan earlier as thought would be needed before dad could see specialist – this was impression given to family. Family started investigating on web for info on nerve endings and specialist.

Oct 15 Sat

Oct 16 Sun

Oct 17 Mon

Told by specialist's secretary that waiting time for scan could be up to a month.

Oct 18 Tue

Rang Nuffield for private scan - too long, managed to get a private appointment for 22 Oct at hospital. Letter received for appointment with specialist for 25 Oct.

Oct 19 Wed

Told not to bother with scan by specialist's secretary, just to come and see specialist. Cancelled scan

Oct 20 Thu

Oct 21 Fri

Eldest son and wife visited bank and building society re mum & dad's finances. Power of attorney signing.

Oct 22 Sat

Oct 23 Sun

Oct 24 Mon

Oct 25 Tue

Dad and eldest daughter went to see specialist at second hospital. He diagnosed MND bulbar palsy. He verbally explained what this meant but no written material was provided. **We were told that the Motor Neurone Disease Association would send us an information pack. It**

was clear that further treatment would be arranged by the specialist's team at this hospital. A further appointment was made for dad to see specialist on 9 November. Dad could still speak a bit and walked with a stick into consulting room. Timeframe for speed of disease not given – specialist couldn't say. Family not warned properly that bulbar palsy is very aggressive version so timeframe could be quick. Total lack of information provided for the family ie carers. Where was practical guidance? Family had to use initiative and source it themselves, including Canadian website about ALC (disease is called this in North America) and MND Association site. Lot of sifting and reading involved to pull out main points. No mention by specialist about referral to local hospital. Macmillan nurse present at this session. **Believed that now dad had seen specialist everything would be put in place by his team of professionals but what in fact happened was nothing. We waited and waited with days going by and no contact made. This is the point that the 'conductor' should have taken control.** Family given impression that someone would pull all health activities for this condition together – all words, no action. Nothing in writing from these visits – no guidance on nutrition on this visit. Dad prescribed Rilutek – family had difficulty getting it from chemists – did eventually from local outlets .

Oct 26 Wed

Local social services in touch re more home help for mum & dad. Dad started taking Rilutek.

Oct 27 Thu

Waiting – no news; no action. Dad getting weaker; mum still at home

Oct 28 Fri ditto

Oct 29 Sat ditto

Oct 30 Sun ditto

Oct 31 Mon ditto

Nov 1 Tue

Mum taken to hospital and diagnosed with fractured hip & Deep Vein Thrombosis (DVT), based on x rays. Sorted out date and time for operation on her hip

Nov 2 Wed

District Nurse came to give dad's flu jab. Local Social Services Care Manager came on scene for first time – she came to visit dad and to look round their house for mobility. Hospital said mum not got fractured hip after all but had DVT

Nov 3 Thu

Hospital said mum not got DVT either!!

Nov 4 Fri

Eldest son and wife visited bank to get forms for direct payments account

Nov 5 Sat

Mum had had around 4 falls in hospital – waiting to be transferred. Dad signed bank forms

Nov 6 Sun

Told that mum transfers to rehabilitative hospital tomorrow. Mum signed bank forms

Nov 7 Mon

Mum transferred to rehabilitative hospital late morning (as younger son and grandson were visiting). Mum not able to attend dad's 85th birthday celebration with family. Dad's birthday meal at local pub. Travelled there by car. Dad could get into and out of the car, walk by himself using a stick, eat a meal by himself (cutting food, chewing & swallowing). He drank a soft drink but couldn't drink beer (possibly too cold) or whisky.

Nov 8 Tue

Eldest daughter with dad

Nov 9 Wed

Dad with eldest son and daughter and daughter-in-law went to see specialist and his team including Macmillan nurse, Speech Therapist & Nutritionist, took blood: results? Dad in wheelchair and couldn't speak at this visit (unlike first visit on 25 Oct). Specialist said dad hadn't lost weight. **But compared with his last visit 15 days ago dad could hardly walk and his speech was virtually unintelligible!!** Specialist talked about breathing kit a) spray b) injection for more serious need. Said would have this on hand. Said he shouldn't have water, which dad had been having. Peg feed came up – specialist said not appropriate at this stage – why? Also said breathing apparatus not suitable for dad because couldn't close it round his mouth (didn't stop them putting oxygen mask on dad in hospital). Dad taking 2 rilutek a day. Told about **light writer** and that it would not take long to get. Advised not to buy one even though we would have done so. Wouldn't give us their one because for local use only. Nutritionist gave family thick drinks and thickener and we thought nutritionist would write to dad's GP – don't know if she did or not – no info. It was not explained to us, the diagnosis having been made, whether we could have had treatment arranged in hospital near where dad lived. **Next appointment for dad to see specialist made for Wed 11 Jan!!**

Nov 10 Thu

Eldest daughter rang district nurse because concerned re dad. First appointment with bank re refusal by them to set up direct payments account for dad's care

Nov 11 Fri

It transpires that second hospital should have written to GP re breathing kit to be ordered, but seems to have been lost in translation.

Nov 12 Sat

Family realised that couldn't give dad care he needed. He was too ill to go and see mum in rehabilitation hospital. **Family felt he didn't have long to go** and so our priority was to get mum and dad together again for however long was left.

Nov 13 Sun

Family with dad

Nov 14 Mon

Today and tomorrow waiting for nutritionist to get prescription drinks – chased her but didn't happen so family asked local GP for prescription as it taking so long. Dad started to write things to us on writing pads as he could no longer say anything. Consultant at rehabilitation hospital saw mum. No feedback re her leg/hip; previously saw matron with concerns, mum's legs badly swollen.

Nov 15 Tue

Family with dad

Nov 16 Wed

District Nurse and Care Manager saw dad at home. Bank again refused to open account for dad for direct payments

Nov 17 Thu

Regional Care Rep from MND Association not able to come and visit dad as she's ill.

Nov 18 Fri

Family with dad

Nov 19 Sat

Dad making porridge for breakfast – had done so every morning previously

Nov 20 Sun

Dad couldn't make porridge this morning because hands too weak. Didn't make it again.

Nov 21 Mon

Family met mum's consultant with concerns, we wanted diagnosis, mum had about 5 falls in rehabilitation hospital, still no x-ray results. Family scoured local area for nursing homes with 2 separate rooms and found one - checked it out with dad's Care Manager

Nov 22 Tue

Out of interest, family visited bank next door to dad's local bank – they said no problem in setting up account for dad even though he never been a customer with them (dad been customer with his own bank for nearly 60 years) but didn't have relevant paperwork at that moment to do it. **From this day, family with dad almost 24 hours a day**

Nov 23 Wed

District nurse visited – what did she think about dad's condition? Different nurse each time so how do they assess? **Why difference in dad not flagged up and GP alerted – seriously ill.** Account set up for dad's direct payments with his Building Society – no problem for them as with his bank.

Nov 24 Thu

Why does the pharmaceutical company prepare rilutek in tablet form? It sometimes took dad several hours to swallow it, unstintingly believing it would cure him.

Nov 25 Fri

Younger son stopped with dad until Monday.

Nov 26 Sat

Dad took about 3 hours to swallow pill in bedroom. Family started to crush rilutek pill as dad having difficulty

Nov 27 Sun

Weekend before dad went into nursing home family called the out of hours doctor as he was choking and couldn't stop (family been with dad, virtually 24 hours a day for 2 weeks so we knew what was happening and what to expect). Lady doctor came – she thought it would settle down but if concerned, call hospital. Not possible to give dad anything. Local nursing home prepared to take in mum and dad

Nov 28 Mon

Eldest daughter stopped with dad until Friday 2 Dec. Mum eventually diagnosed with osteoarthritis, which we knew anyway!

Nov 29 Tue

GP visited dad, seemed shocked as before, with his deterioration. MND Association Regional Care Rep came to visit dad and also phoned GP re whereabouts of breathing kit. Told it would be there at beginning of December – it never arrived – we were never told where it was. Family phoned local therapist who said she knew about dad but hadn't received referral from specialist yet.

Nov 30 Wed

MND Association Rep pushed for lightwriter among other things; we realised it had not been ordered on 9 Nov as agreed; we said we'd buy one, but were told hospital would arrange it. Caused 3 week delay.

Dad incredibly weak, in night took him around 15-20 mins to put light on in his room, get from bed with stick to bathroom next door, about 6 paces & back again.

He had to use chest of drawers to pull himself out of bed. During last few weeks, we'd be blending & sieving all food so dad could swallow it. The two care assistants that helped looked after dad for several hours in the mornings over the last few weeks were brilliant (they had looked after mum too)

Dec 1 Thu

Family became so desperate for help that at 8pm, eldest son contacted local Macmillan Unit.

Even though we had been in touch with hospital over last few weeks, no-one took on board how desperately ill dad was. **He should have been in a hospice before now.**

Dec 2 Fri

Mum moved from rehabilitation hospital to nursing home in morning. GP came to see dad and we asked him to refer dad to Professor at local hospital. We thought he should have started process to have dad admitted into Macmillan Unit. Took dad into nursing home in the afternoon – first time dad and mum had seen each other for about 3 weeks – they had very emotional reunion. Family in tears.

Dec 3 Sat

Mum fell and banged arm at nursing home in front of dad (which we didn't know about) – seriousness of it not appreciated at this time by staff at the home.

Dec 4 Sun

Family started to feel nursing home was the wrong place for dad because they had underestimated the care he needed. Family believed he needed specialist palliative care.

Dec 5 Mon

Concerns over comfort & dignity for dad; also left alone for too long at a time; family had to keep intervening & made to feel in the way. Asked by home to back off to let them manage him. How could we when they seemed less sure of what to do than his family? **It wasn't just the nursing home; we believe that no nursing home is suitable for someone with MND-bulbar palsy or any rapid deteriorating terminal illness. They need to be looked after by specialist palliative nurses and consultants.**

Dec 6 Tue

Speech therapist saw dad, no notes been sent through from hospital. This was the earliest date she could fit in to see dad. Did therapist ever receive referral notes from hospital? No-one ever said. All these health professionals were contacted by family or his Care Manager ringing them and arranging for them to see dad, with a family member always there.

Dec 7 Wed

GP visited dad (visibly shocked) & prescribed scopoderm patches to dry up mucous. Care Manager visited while family visiting mum. We showed her mum's arm and she immediately spoke to matron, who asked GP to check Mum as well. Daughter took mum to local hospital in taxi for x-ray as shortage of nursing home staff. Mum had fractured her upper right arm and severely bruised her right elbow. At hospital for nearly 4 hours. This all had effect on dad. The staff seemed to forget all his senses were there, even though he couldn't communicate.

Dec 8 Thu

Community Physio visited dad. Have to ask – with dad so ill, what use physio? Profiling bed for dad delivered; lightwriter delivered (too late by now to make much difference)

Dec 9 Fri

Nursing home couldn't seem to understand the dietary and mouth care requirements for dad and so meals provided were completely unsuitable. They ended up giving him soup and ice-cream.

Dec 10 Sat

Dad just able to stand in nursing home but not walk. Went to sit in lounge.

Dec 11 Sun

Dad too weak to get on commode in his room

Dec 12 Mon

Community Macmillan Nurse visited dad, asked her to emphasise mouth care to staff, among other things. This is when dad first wrote that he wanted to go into hospital. Macmillan Nurse suggested he attend day care centre at unit. Why did she not say that dad needed palliative care?

Dec 13 Tue

Dad not good; food not being prepared correctly for dad to eat, nutritionist should have been involved weeks ago, it was up to family again to keep asking for it. Isn't it standard to monitor food intake for any resident? If this was being done with dad, shouldn't red lights have been flashing? He wasn't/couldn't eat what was put before him.

Dec 14 Wed

Visit to hospital physio for mum

Dec 15 Thu

Community physio for dad. GP & Professor saw dad & between them referred him to local hospital for peg feed operation. He'd not eaten for days. Malnourished and dehydrated. He was really hungry. Dad again asked to go into hospital. Family eventually bought scopoderm patches in Derby and London so dad could start using them, as there was a distribution shortage, again the family were running around sorting this out. Admitted to Medical Assessment Unit at local hospital in afternoon. Why wasn't he taken up to the ward straight away? He did not need assessing as it was known why he was admitted. Professor also diagnosed dad as being very depressed and suggested treatment after peg operation. Wasn't it obvious how ill dad was?

Dec 16 Fri

Last night in Medical Assessment Unit dad had been left lying flat in a wet bed with no mouth care & sore eyes; family 'grabbed' nurse straight away and insisted that the bed and dad be changed. They waited in the day room and saw that not only did they change the bed but had put a pad on dad – obviously they STILL did not realise that he could not communicate because of the MND and not because he was senile, which he wasn't, neither was he incontinent – the disease doesn't do either of these things to its victims. Seems that they think because he cannot speak that he is also unable to understand – stressed that this was not the case and that they needed to check him on a more regular basis. Dad also not receiving fluids. He was transferred to general ward in evening and again family found him lying flat & looking bad. Staff nurse asked what his condition was & how it was spelt. Family did not feel confident about leaving dad there.

Dec 17 Sat

Dad in really bad condition, on drip, nil by mouth, even though speech therapist had left instructions about mouth care; no link between community services & equivalent hospital ones. Eldest daughter telephoned eldest brother to say upset that she had found dad lying flat and that, having removed the IV drip himself because uncomfortable, he was not receiving any fluids. Son went straight down to ward and demanded to see a registrar. Was told that the registrar for relevant consultant was not on duty but son demanded to see registrar on call and that he was not going to wait all day, but would wait a reasonable time. Registrar came within half an hour and everything explained to him about what had not been happening and care dad receiving not good enough; registrar agreed that general nursing care should be given as a matter of course. He also said he would have a word with the staff and there was some improvement in dad's care after this. He also made it clear to staff that dad could understand everything even if he could not talk and that it was possible to communicate with dad by writing notes. Family were given the impression when they were talking to some staff that they were merely being tolerated and just given time to have a moan but that nothing would be done. Nursing sister on duty at the time not very helpful and receptionist was very supercilious in her attitude to us. Again highlighted fact that dad was in the wrong environment; they were not geared up to dealing with the terminally ill, let alone MND as they were a general medical ward

Dec 18 Sun

Still manufacturing problem with scopoderm patches so all family scouring outlets to buy them over the counter.

Dec 19 Mon

Dad had peg feed fitted & was on it for 20 hours out of 24 to start with as he was so below his weight & reserve weight. Not had good appetite during Sept, Oct, Nov, Dec – good two months of hardly eating. Why did medical professionals not see this sooner, when the family did?

Dec 20 Tue

Dad seemed to pick up, he wrote more. Hospital talking about discharging dad either Wed or Thurs. Stressed that this was no good as the home could not cope with him, not only feeding him 20hrs out of 24hrs, but not look after him full stop. Eventually told that he would not be discharged until at least 28th because the equipment would not be delivered to the home until then. The only time we felt thankful that it was the holiday period.

Dec 21 Wed

Also checking mum ok too. Occupational Therapist ordered special cushions for mum and dad.

Dec 22 Thu

Dad lot better today, relatively speaking; sat in chair by bed for two hours.

Dec 23 Fri

After hopeful signs of yesterday, dad deteriorating again. Difficult for him to read or write anything; sleeping a lot.

Dec 24 Sat Christmas Eve

Same as yesterday. Family did not know what to do as weekend - **everything seems to stop at the weekend, even though dad's illness doesn't!** Fewer resources as Christmas weekend.

Dec 25 Sun Christmas Day

Waiting game again today. How is it only family seem to know how ill dad is? That's why we've had to manage it all, couldn't spend quality time with him, too busy chasing everyone. Brought mum to visit dad this morning. Very pleased to see him but did not understand how ill he was.

Dec 26 Mon Boxing Day

Family decided to contact local community Macmillan Nurse for her to see dad – not able to come until tomorrow at earliest because Boxing Day and no-one around

Dec 27 Tue

Family left a voicemail message for Macmillan Nurse. Finally told that we had to deal with hospital Macmillan nurse not the community one. **Again lack of communication – hospital Macmillan nurse should have been informed as soon as dad was admitted to City, he could have been in hospice by now**

Dec 28 Wed

Hospital Macmillan Nurse came to see dad. She seemed unhappy with situation – family spoke with her for about 2 hrs – she made copious notes. We felt that at last someone was taking on board how extremely ill dad is. Constant effort for family to make sure dad looked after properly. Treatment from general nursing staff had improved – particularly good input from 2 staff nurses and male nurse on the ward. But still he needed more intensive one-to-one care for the condition he was in. Because he couldn't communicate he was left alone. MND

Association information says that if treatment carried out properly, should be no need for emergency intervention. Well – can only conclude that treatment not carried out properly because had need for emergency intervention all down the line!

Dec 29 Thu

Hospital Macmillan Nurse came to see dad again and was going to contact Palliative Consultant to come and see him. Using suction right down dad's throat now to remove mucous. His throat bleeding and sore. Dad not looking well at all in evening – could hardly raise his hand to wave goodbye. What happened to non-invasive ventilation? Why not tried? Did they not have the equipment? If not, why not asked for before now? One of the nurses overheard commenting about dad's bad mouth care.

Dec 30 Fri

Hospital called 7.30am, dad not good. Palliative Consultant and Hospital Macmillan Nurse visited. Family hit phones & got message to dad's consultant, who came to hospital later in morning; Doctor who performed peg feed op came in with his team, plus registrar on call. At one point all these professionals in same room as family. Dad needed them at diagnosis, not at end when little left to do! Dad too ill to move out of hospital, so moved to side ward.

Dad died at 9.48pm. His 4 children, daughter-in-law and two grandchildren were with him; mum saw him earlier in day.

Where was the care and dignity that our father should have had? It was not the fact that our father died, it was what he had to endure at the end of his life that is unforgivable

Dec 31 Sat New Year's Eve**Jan 1 Sun New Year's Day****Jan 2 Mon****Jan 3 Tues****Jan 4 Wed****Jan 5 Thurs****Jan 6 Fri**

Macmillan Nurse contacted family to meet up with her and then again with relevant local organisations to discuss dad's case and learn from it.

Jan 7 Sat**Jan 8 Sun****Jan 9 Mon****Jan 10 Tues****Jan 11 Wed**

Would have been appointment for dad to see specialist consultant today to see how he was getting on!

Jan 12 Thurs**Jan 13 Fri**

Dad's funeral – process of writing The Findlay Report began

From April 2006

Start distributing copies of The Findlay Report locally and nationally; series of meetings with hospital staff; consultants; PCT where dad treated.

2007 – present: our work goes on