

## Carers Network Day

### Feedback from 7 January 2011

Table No.	AM Colour	PM Colour
1	Blue	Green
2	Blue	Green
3	Blue	Green
4	Blue	Green
5	Yellow	Green
6	Yellow	Green
7	White	White
8	Yellow	Green

**Blue** Patient and Carers Experiences in Hospitals

**Yellow** Information Revolution/Choice and Control

**White** Change to HCC day services/residential respite for people with learning difficulties.

**Green** Carers Strategy and Personalisation

#### Table One - Patients and Carers experiences inside Hospital settings

##### Blue sky thinking

- Go back to basic training none of this University training go back to training on the wards.
- Communication between all people involved in care of the individual ie Carers, Staff, social workers & other professionals.
- When looking after someone on the wards with sight impairments at meal times use the clock face for explaining what food is where on the plate.
- Also make sure the food and other items are within their reach.
- Also to have staff available to help with feeding of patients with Dementia, stroke, Learning disabilities, mental health and other physical disabilities.
- Paramedics need to be informed of health conditions which could affect the way in which someone gets in or out of an ambulance (hospital Transport)
- One ladies father was blind and fell when getting out of the ambulance as no one had bothered to ask if he needed any help.
- Better communication when being discharged from Hospital and making sure everyone involved in the discharge has done what they were supposed to do.(Goes back to communication).
- Informal carers need some training to look after the person they are caring for.
- Carers have enough to worry about with making sure everything is ready at home, they need more than being shown quickly how to provide care ie changing a catheter bag? Or Peg feeding.
- Make sure Carer Packages are in place and ready to happen before the patient leaves hospital.
- Get rid of mixed sex wards.
- Medication Discharge needs to be ready when the person is being discharged, saves bed blocking or patients having to sit in waiting rooms for hours.
- Private rooms available for distressing news.

### Three main points

- Speedy communication on all parties involved in the care done with sensitivity.
- To be treated holistically (service users and carers)
- Training for all hospital staff, how to communicate effectively with learning disabilities, mental health, physical disabilities, sight and hearing impairments

### Table Two - Patients and Carers experiences inside Hospital settings

#### Ideas, suggestions, information – blue sky thinking

- Objection to the way older people are put on a geriatric ward (why split up by age?) – experience of being on a very quiet ward – lonely. Attitude of nurses was terrible – lax and not attentive.
- A & E excellent
- D Level – very good / excellent
- G Level at SGH – very poor
- In isolation ward – same staff member gave tea and cleaned the bins.
- Nurses were good at feeding.
- 3 moves in a week.
- Some of the younger doctors don't have a good bedside manner – and feel as though lack of experience.
- 2005 discharge was poorly planned – OT staff would have taken the wheelchair away, leaving patient without wheelchair!
- Mental Health (DOP)  
I/P Psychiatric care. Patient ready for discharge but there was a problem with accommodation (which had contributed towards the admission). CMHT had known that.  
Patients were told 45 minutes before a CPA meeting so family had no opportunity to be involved.  
Members of staff that were available were inexperienced – did their best but could not help properly.  
In patient care was much better. Staff very stretched and inexperienced, but their attitude was good and atmosphere was good.
- Intensive care – staff were too busy to feed patients, but family were told the patient would be too ill to be at home.
- Ward environments – “men peeing all over the place”. Patient developed c. diff. Multiple moves after a successful operation, then a long stay. Isolation was not good – food trolleys in and out of the room without washing their hands. Ward not clean enough.
- Praise for paramedics and rapid responders – excellent admission through A&E. Never seemed to be in the same bed for 2 or 3 days running. After a move between wards, food – he had to have whatever was left over.
- No consideration for the carer, who has a small holding. No planning, no advance notice, GP hadn't been informed – just a phone call saying husband ready to come home now.
- Other patient was being a nuisance – shouting. Man in bed next door passed away – was moved onto mortuary trolley during visiting hours – very distressing.
- Patient eventually home at 9.45pm.
- 3 months wait for rehab at home
- Porter wouldn't come outside with a wheelchair because he didn't have a coat on.

- Intensive care was good, but on the general wards, very poor. Food late or absent. No evidence of the nurses actually doing nursing with patients, the nurses seem to gather around the nurses station talking.
- Patient went to the general - c. diff, MRSA, lost 3 stone, staff on the ward told wife that he was "fine" – so wife told daughter, not to worry, go to work. Couldn't get any sense.
- Attitude of consultant – her manner was bad. RSH – privately run on contract for the NHS, excellent attitude, couldn't do enough. Nice, friendly and kind – all of the staff.

### **Three main points to make from AM workshop:**

1. There needs to be good discharge planning (involving the carer). Experiences related in the group demonstrated either very poor planning, or complete lack of planning. Wife received a call – "husband ready to come home now" – then wife sent back home for paperwork – patient home at 9.45pm. Also lack of equipment at home sorted out.
2. Carers need to be involved and informed fully, both for discharge and during the stay and staff need to remember that carers may also have commitments other than the person who is in hospital – family ties, other dependents, estates, etc.
3. The attitude of staff is incredibly important. Two experiences of being on a geriatric ward where patients felt expendable. Patients not fed, response to call bells appeared to be slow or absent. Carers reported not seeing nurses actually working with patients, rather standing around, or walking from place to place.

### **Table 3 - Patients and Carers experiences inside Hospital settings**

#### **Ideas, suggestions, information – blue sky thinking**

- Care Plan – can go straight through to children's ward as has this.
- Efficient use at hospital for hernia operation.
- Patient not understanding what is going on during process from A & E forward. Lack of communication with carer.
- Communication with learning difficulties, or if people can't speak. Picture cards could be used.
- Confidentiality being a barrier.
- Could things be written down.

#### **Discharge Procedure**

- Anxiety- after op, asked for emotional support. Did it for a week and went on holiday – needed extended care, lack of consistency and communication.
- Transport not ready when discharge is. People being held.
- Transferring people at unsuitable hours – 12.00/1.00am.
- Rudeness of hospital staff.
- Staff doing handover in ward. Patients hearing confidential information.
- Complained to PALs. PALs went to matron instead of patient.
- Doctors talk down to elderly. Ignoring requests.
- Patients not eating as food is being put too far away.
- Patients coming out of hospital incontinent.
- Data Protection – not informing carers/family important info unless power of attorney.
- Judgement of staff.
- Exceptional staff and care in private care.
- Info for carers.
- Lack of info.
- No letter sent home after discharge for carer to check.
- If ambulance is called. Patient is taken with no contact to carer.

- Lack of communication between hospital and GP
- Medication
- Hospital doesn't check temperature enough
- Commode not always available.
- Medication e.g. paracetamol, not given often enough.
- Boards behind bed not used for info anymore – Basingstoke.
- Could have an "All About Me" book to help staff understand patients likes and dislikes.
- GP Experience is better than Dr in hospital.
- Communication is better.
- Hospital not always listen to GP referral.
- Younger doctors less confident.

### **Three main points from AM Session**

1. Communication
  - a. GP and hospital
  - b. Between staff
  - c. Learning difficulties
  - d. Confidentiality being a barrier
  - e. Data Protection (Power of Attorney)
  - f. White board above bed
2. Proper discharge package
  - a. To go to carer and patient
  - b. Medication instructions
  - c. Accurate!
3. Staff
  - a. Listening to patient and carer.
  - b. Not being judgemental
  - c. Talking to patient and carer together.
  - d. Actually listen and document.
  - e. Not discuss patients on ward.
  - f. Handover in private and in depth
  - g. Lack of awareness- training needs.

### **Table One - Carers Strategy / Carers and Personalisation**

#### **Blue sky thinking**

- Advocacy - Social workers should be experienced in the services they are assessing.
- There needs to be more trained advocates in knowing the correct procedures of what they are advocating for.
- Better publicity on the help available to individuals and how to access the services.
- Advice - GP's should be more prepared to support and advertise the great services available, who provides them for any individual who might want to access them.
- Advertise in local MP surgeries, Hospitals, Wellbeing Centres, local libraries,
- Local and national newspapers, local radio and websites.
- Support – Respite must be flexible and a very good standard of care to be provides from care agencies, and informal cares with appropriate training.

#### **Three main points**

- Respite flexible services. Advocates needed for information and support.

- Professionals having a better understanding of carers needs, and for the person being cared for to be treated with dignity and respect.
- Better advertising of all the services available to carers and professionals.

## **Table Two - Carers Strategy / Carers and Personalisation workshop**

### **Ideas, suggestions, information – blue sky thinking:**

- Cut out wastage- so many disposable items.
- Bring back a matron – keep staff on their toes and encourage a better attitude.
- Care workers were very good, but some appeared to be less focussed. Would like a better rate of pay for the care workers.
- Advocacy, Advice and Support – carers want respect and with respect, other things will fall into place.
- SDS, DP or Vouchers:
- “We’ve still got our marbles” – would prefer the direct funding, but would need guidance and support at the same time. It would also depend on the funding available – and how much paperwork etc, - some of us don’t want to be bothered with NI and tax, etc.
- Need somebody to guide, to know the answers – where to get the help, etc.
- County council – problem solving /flexibility – paid for driving lessons as a refresher for a carer whose husband became ill – enabled er to get out and about.
- Enjoyed meeting other carers – “you think you’re the only one, but you’re not”.
- Key worker scheme
- Funding – would we support additional taxes.

### **Three main points from PM workshop:**

1. A break for carers, with someone reliable.
2. Good quality advice, advocacy, support, which would enable us to go forward and find more help. Independent organisations such as Carers Together – and they should be properly funded.
3. GP availability – can book double appointments if needed. Can be tricky to get to the GP – the practise is close by, but can’t walk there.

## **Table Three - Carers Strategy / Carers and Personalisation workshop**

### **Ideas, suggestions, information – blue sky thinking**

Help to make a care package for direct payments.

Advocacy – Difficult to find advocacy. Where it’s available, don’t know it’s available.

- Empowering people, rather than doing it for them.
- Support and back up. Important to have someone with you. Very important. Should be easy access.
- Advice – CAB, MENCAP, CT, Library.  
Leaflets should be given to patients/carers by professionals instead of being left to get from a table. At point of diagnosis – someone to explain meanings.
- Support – Should be somewhere to go directly after diagnosis – GP support. CALL line.

- Inclusion of carer – When patient comes out of hospital, carer should be consulted and informed as well as patient carers assessment. Write your own care plan and see if a professional will back you up – similar to birth plan.
- Care Planning – Needs to be done together – Society needs to join together and realise caring is an important role.
- Funding – Carers in general don't know where to get funding. Direct Payments.
- Carers Breaks – Difficult emotionally to put cared for in respite. Should be entitled to a holiday. May not take it, but should be available.
- Day services closing – have to find own services.
- Directory of used and trusted carers.

### **Three main points from workshop**

1. Advocacy – GPs to provide information at time needed, e.g. discharge.
2. Care Plan – Write your own care plan and see if a professional will back you up. Similar to birth plan.
3. Direct Payments – Difficult. Hard enough to care, let alone do all paperwork, tax etc.

### **Table 4 – Patient and Carers Experiences in Hospitals**

#### **Ideas, suggestions, information – blue sky thinking:**

- N.F. planned booking in procedure – patient asked to contact Milton Keynes to make booking – then contact the hospital-lack of communication between hospital and booking centre – 5 cases of weeks of delays before appointment.
- Lack of communication is main problem.
- Lymington Hospital seems to have communication problems.
- Communication between hospital / ambulance/ GP was lacking.
- When first time in hospital, you don't know the procedure and don't know what should happen (QA Portsmouth).
- Too many visitors for each patient.
- Lymington Hospital – no complain on admission relating to Dementia patient.
- Dementia patient locked in toilet – got into panic – nurses didn't realise he was gone.
- Not enough training for hospital staff with dementia patients.
- Lymington Hospital was very good.
- Experiences very different for different people in different hospitals – also between different wards within hospital.
- Advocate would be beneficial as no knowledge.
- Patient left on bed on arrival from hospital in Cornwall.
- Late night move from nursing home to hospital with no information given to carer until it had happened – Basingstoke Hospital.
- Discharge late at night – put in taxi 1.00am – not good. Gone in with hernia – Southampton General.
- Moved 5 wards in 5 days in QA. Family not told. Wife had disability problems and found it difficult to keep tracking him down. Treatment was great. Moved too many times.
- Taken home in wheelchair after being in bed for 5 months.
- Patient moved at 7.00pm. Porter wouldn't wait to get patients personal possessions.

- Not easy for patient who know their rights – most patients are unable to speak up when they are ill.
- Portsmouth QA – we didn't know there was an information book – and no info for carers/family. Guidance needed for carer as patient often can't read / use info book.
- Carers not used as information regarding patients. Carer often knows / especially dementia parents / what is best. Hospital staff ask patient when carer knows better.
- GP recognises carer and given information. Same not true when in hospital.
- Not easy to get update on patient progress if patient can't tell their carer themselves.
- Time is an issue in providing good quality nursing care.
- Feeding / hydration – needs to be provided in a place where patient can access it.
- Delay on discharge because of social worker not attending soon enough. (Hythe). Good once in place.
- Emergency team were great for 6 weeks after discharge (Hythe).
- Bed experience of emergency care team. Left patient with carer as she was there, in order to go to other patients who may have been on own. Could be in bed from 7.00pm to 11.00am because that's when carer came.
- Care package for dementia needs strict routine.
- Patient may be ready for discharge but no transport is available and ready to go but pharmacy has not provided medication.
- Couldn't carer go and collect medication?
- Medical information gets shared between professional – not so with 'care' information.
- Big differences in experiences between hospitals – some great – others poor. QA good communication.
- Question of patient 'wandering' is an issue.
- Training of professionals to appreciate what carers needs are as well as patients.

### **Three main points of workshop:**

1. Communication with carers – providing information to, and getting information from.
2. Provision of information – patients and carers don't know what to expect the first time they go into hospital.
3. Staffing levels – need appropriate number of staff to provide quality care / nursing to every patient.

### **Table 4 – Carers Strategy and Personalisation**

#### **Ideas, suggestions, information – blue sky thinking:**

- Basingstoke advocacy – hard help service to provide, as advocate must act as the client wants – rather than what they themselves think.
- Some in Eastleigh and Southampton, one advocates for older people.
- Have been asked to act as a volunteer advocate.
- There is a need.
- Access is a problem – must be referred if using a professional service.
- Advice – CAB, from fellow carers – professional carers, carers support groups.
- Social worker provide only limited advice.
- People don't always seek information from certain organisations as they think they don't fit into their 'criteria'.
- Good to keep in touch with fellow carers who can give advice based on their experiences.
- NHS support – excellent – equipment, OT – good experience.

- If you don't know you are entitled to certain things, you can go out and buy things you don't need to.
- Not knowing what to ask is a big problem.
- Quality of information / relevance of information.
- Carers not aware that they themselves are entitled to an assessment.
- Older carers sometimes guarded about how much they 'tell' social services – don't want to end up in a care home.
- These network days are good way of getting carers views across.
- Carers should be registered as a 'carer' with their GP.
- Carers allowance should be minimum wage.
- Carers allowance stops at retirement age – state pension is for everyone.
- Is Carers Allowance / Attendance Allowance / Disability Living Allowance all to be amalgamated?
- Why is mobility portion of DLA not addressed in AA?
- Pension should not affect benefits.
- Good to be able to chose their own support. Everyone needs different support.
- Respite – hard to get. Can only self fund. SSAFA help with respite.
- Even self funders need the information – often don't know where to get it.
- Get break twice a year.
- Bournemouth Hospital offer help with respite.
- Care planning – if you don't / can't compare your care package with others then you don't know.
- MS patient on DP – works better as they are dealing directly with agencies.
- Advice and training is required (and is available) to help in use of DP.
- Funding – most important.
- Thushold of financial saving should be lowered so they're not worried by not being entitled to care services if they have savings.
- Positive – CT Sitting Service – brilliant.
- Funding of Carers Support Organisations helps.

### **Three main points of workshop:**

1. Information – to be delivered at the point of need.
2. Communication.
3. Funding.

### **Table 5 – The Information Revolution**

1. A health and welfare passport. A card that can be read by mini computer in ambulance.
2. An advisory service should be set up to assist people to access their health and welfare records. A human advisory service (especially for those who have difficulty with technology)
3. Security – Information and reassurance for public concerns on security. A flag system to show who has accessed your information and when.
4. A comedy skit should be devised to show some or the "Comedy of Errors" that have occurred to carers.

### **Table 5 - Carers Strategy and Personalisation**

#### **Three main points from the PM Workshop**

1. An SOS Phone Line for signposting to the correct services for advocacy and advice and support.
2. Respite care should be increased and treated as a priority (not reduced to fit in with budget cuts).

### **Table 6 – An Information Revolution – Three main points**

1. Group want to be involved in their own health care and in control of it. i.e. a print out of medical info after each consultation – handed to them in private so they have an update of each stage of their care. Treat people as people, independently and not fitted into the closest box.
2. The personal hands on approach at initial point of care/contact when at most vulnerable. Not just given a diagnosis and sent on their way.
3. Reaching people who are on their own and vulnerable. Who don't belong to any support groups and live in isolation. "Information pooling" by working together with postman / neighbourhood watch schemes / GP / CPN / District Nurse / Advocates / Family Members / Churches / Council / Social Workers. Telecare info etc. sent in the post.

### **Table 8 – Information Revolution/Choice and Control**

#### **Three main points from workshop**

1. Availability of understandable, plain English, truthful, information to allow us to make informed decision and to have the confidence to fight for what is required.
2. Clear specification of need.
3. Cloning CT Advocacy Worker.

#### **Ideas, suggestions, information – blue sky thinking for PM workshop:**

- Would like GPs to have a "patient appraisal" each year with each patient.
- Being able to see own notes.
- IT can help identify possible problems so we can prepare for them.
- Really understanding patients feelings.
- Top-up "fees"
- Should confidentiality be more fair – records very important. E.g. differences between Southampton and Hampshire.
- Information how are GP practices run and what guidelines do they work to, e.g. cost of medication changes, medication prescribed. Finances behind GP practices puts patient on equal to doctors.
- Access to information should be free or if a fee consistent in the whole country.
- Information available.
- Training in medical person / of interpersonal skills.
- Risk and liabilities.
- Concern – who looks after the quality control of the databases.
- Concerns – Confidentiality. Will they be kept up to date. -> Misuse of data -> Release without permission.
- How to deal with "patients" with mental health problems who won't or can't share records with people who know.
- Provision for those who need to have access.
- Mechanisms
- Powers of Attorney.

- Assessment process to be available and transparent – how did they arrive at what the needs are?
- Democratisation of services.
- Put admin into voluntary services.
- Still need to be able to just ask for the information.
- Easier access to hospital results without having to go to hospital.
- Invite people needing care to “say” what their needs are.
- Patient Participation Groups.
- IT could give you “passcode” access to your records to “prove” who you are.
- Educate patients so they know what the choices are.
- K.I.S.S
- Help patients work out what would be best for them.

**Three main points from Workshop:**

1. Confidentiality – all aspects.
2. Educate patients and their carers on what is available so they can make an informed choice (including family where appropriate).
3. Information available as to how cost is driving the decision on what medical care people receive.
4. Patient choice.

**Table 6 - Carers Strategy / Carers and Personalisation – PM Workshop**

Services Available	Services Needed	Services Not Needed	Services Preferred
Carers Together. Choices. Solent Mind. Age Concern. Hospital Discharge Team (Questionable? Should not have to ask for aftercare) – lots sent home without aftercare because they did not ask for it because no one tells them about it.	Knowing Entitlement. Signposting Services. Admiral Nurse Service. Transport Services. Better communication between medical professions. More voluntary services. Information put in library. Better services from local GPs and more person centred service. More visits from social workers, District Nurses. More hospital check ups / care reviews. Quicker response to calls from all services. Medication follow up from GPs, not just continual repeat prescriptions. Regular pick up of soiled incontinence pads – not fortnightly visits.	Social Workers not to be present at hospital discharge as they make things difficult. Incompetent Social Workers. Contact Centres – want to speak to real person.	More personal services. Admiral Nurses in all areas. Hospital team in place. Prefer nursing team to make care and after care package decisions. Continuity of service providers, Social Worker, Carers visiting. Separate assessments – not done in front of cared for – as important info not said due to risk of upset. Incontinence Team- GP to refer automatically when appropriate.

Inclusion of carers.

Information / resource days with workshops and feedback.

Funding – Not from GPs – but from local council.

Preferred: Support voluntary organisation that know what real people want and ask. ASK US!

**Key:** Carers Break – Respite – Fight for your entitlement. Get yourself a Social Worker, Advocate, Personal Budget Plan Package, PPF.

Day/care 1-2 days. 8 Weeks respite. Sitting service.

**Key Points:**

Highest priority

1. Choice
2. Knowledge
3. Service Availability

More choice provided -> fewer Vouchers with limited choice of provider

**Table 7 - Changes to Hampshire day services and residential respite for people with learning difficulties.**

- Some day services not fit for purpose but some very good – fears that the good will be thrown out with the bad.
- For the more able who will get personalised services – these may be very fragmented – will there be enough trained support workers?
- Will some people fall through the net?
- How will transport be arranged to such a diverse range of activities with everyone going to different things at different times.
- Will require excellent brokerage to organise it properly and excellent (paid) advocate to make sure everyone gets the best service.
- Some carers elderly or not willing to take on the complexities of new system. May not want to employ own support workers.
- Company – some people with LD enjoy the company of other with LD and may miss this if joining mainstream activities.
- Also they like be able to help the less able people at the day centre – will not have this opportunity anymore.
- Maybe parents with accessible cars could offer lift and charge for petrol.
- Day service officers could be employed as PAs in new system so their skills are not lost.

## **Table 7 Hospitals**

At the General – they put everyone who is ‘difficult’ in one ward – so people with LD may be with alcoholics and people with Alzheimer’s. Parents feel they have to stay 24/7 to make sure their son/daughter is cared for properly as other patients may be louder and get most of the attention and there doesn’t seem to be enough staff.

## **Table 7 Carers**

- There should be true recognition of what carers do and the money they save the council.
- There should be a partnership approach between Social Services and the carer with the services providing backup as needed.
- Advocacy for carers is needed and support for organisations that provide advocacy.

## **Table 7 Contributions Policy**

Point 2 on consultation document:

- Should be individual assessment of costs (such as clothing, washing, continence pads etc) not a blanket sum for everyone.
4. People need a small amount of free income for incidental expenses and autonomy.
  7. Carers services should be free.

## Summary Feedback

- AM. Attitude of staff in hospital made a big difference.
- AM. Communication with carers – getting information to and from.
- AM. Health & Welfare “passport” – card that can be read.
  - Advisory service from humans to help with terminology.
  - Security.
  - Comedy skit to show errors.
- AM. More involved in all health care – take a record home.
  - Personal care – better explanations.
  - Vulnerable & isolated ways to write.
- AM. Patients and carers need education on what is available.
- AM. Anxiety over changes – concern over less able to speak up – advocacy greater need.
- AM. Communication – especially of difficulties.
- AM. Better training for professionals re special needs e.g. Dementia – on discharge carers are also trained in specialisms.
  
- PM. Good quality advice vital from independent source.
- PM. Need for information to be delivered at time of need.
- PM. SOS phonenumber to point to correct service – independent.
- PM. Choice of what services and knowledge about them.
- PM. Information – truthful, plain and able to make decision.
- PM. Contributions policy – carers should not have to pay for respite.
- PM. Writing own care plan.
  - Need support for support workers too.
- PM. Professionals need to understand needs of carers - focus on dignity.