

## Feedback from the Carers Event 25<sup>th</sup> November 2016

### Group 1

#### Question 1- As a carer what is your experience of GP's and other healthcare professionals:

- GP – no issues and they are aware that I am a carer
- GP attended out of hours as I was unable to get to any A & E when person she was caring for health deteriorated
- District Nursing team always attend and give excellent care
- A particular problem one carer faces is her mother lives in North Tyneside, her GP is in Newcastle and the carer lives in Northumberland
- You don't know what you don't know
- Could GP's know what is happening in adjoining areas
- GP's don't ask if you are a carer
- It is difficult to discuss the care of the person you are caring for because you are not identified as a carer and they use confidentiality as a reason to blank you
- Could an agreed password be a way around this problem
- If you as a carer are not a patient at the same practice as the patient you are a carer for – that throws up even more barriers
- The clinical systems needs to be able to flag on a patients records that they are being cared for and who the carer is
- The clinical system also needs to flag carers
- A carer says it is much easier now they have retired as they are able to invest more time into the person they are caring for
- Could every GP ask every patient if they are a carer – this could then lead onto other things
- People maybe don't understand what the 'key is'
- Carers don't always identify themselves as a carer
- Need to think about other questions to ask patients – so they identify themselves as carer
- Don't see doctor much
- In the past I went with my husband. We were given no information over the past two years. I have been a full time carer.
- Not about impact of caring role (visit) GP knows husband is ill.
- Better if name on carers register
- No idea if on register
- GP great and aware of my carers role
- Whitley Bay Sally Richardson. Used Sally quite a lot to pick brain/get information.
- Unsure if have carers information leaflet on notice board or within reception.
- No experience yet. Going on Tuesday hoping that will help me as a carer
- I have been a carer since child was born
- Have been reluctant to go to the GP in the past.
- Being a carer is affecting my health, forgetful not eating etc.
- 1 day a week- walking GRP –my time to re-charge batteries. Already a member of the GRP before hubby got ill.
- Some GPs system flash up carers name and who they are caring for ie Molineux
- Can easily get appointments. Rigid appointment times challenging.
- Not enough time to explain what was going on.

## Question 2 - What are your experiences of hospital discharge?

- Positive experience – received operation and prior to discharge social service implemented care plan, got District Nurse support, carer support provided, hospital informed all agencies (the person getting the op was the carer)
- Aware of situation where lack of support
- Examples of delays in getting appropriate support (2 weeks) still awaiting DN support. Having impact on main carer and their health
- Planned discharge but due to delays in medication it was 6pm at night
- Good processes in place but not always followed through
- As a carer e.g. good examples of the discharge process, awareness of commitments, good communication
- Carers confidence to speak up
- Support mechanisms in place for appointments – appropriate times, dates, notice periods
- Multiple admissions/discharges between hospitals
- Poor communication e.g. dementia, patient given info and not relayed to carer and vice versa. Both written and verbal
- Lack of confidence that discharges are appropriate to needs
- Discharge letters – long process and not easily communicated to patient and families
- Late night discharges happening when there is no health care support available
- Excellent for me. Help with chair right to door-couldn't fault them. Discharge plan in place. No discharge meeting. Carer should be involved.
- OT came out to give advice on safe transfer etc.
- Not help at all. NTG
- Recent experience at NSECH A and E. I was told that I could ring the Crisis team. PT in 10 days. However, I was not involved in planning discharge. PT passed from one service to another e.g. MH service and others.
- Discharged home and still suicidal – Given me support on how to cope
- We could give more support Paula at the Carers Centre is fantastic!!
- No hospital admission should be able to speak to professional on our own without an appointment.
- Important to be a part of discharge discussion, able to talk to professionals on our own.
- Personal experience of discharge- unsafe discharge. No conversation about needs.
- Fractured hip/pelvis in the last two years, bed ridden. Put in bed at 1.30am in the morning complaint was put in. No plan in place. No coat- freezing weather. Only wearing a night dress. PT should never have been discharged. Crisis team from LA had to step in. Should have care met by NHS. Some form of rehab was required.
- Problem with hospital discharge
- Crisis team from LA had to step in. Should have care met by the NHS.
- Some form of re-hab was required
- Problem with hospital discharge
- Shocking does not work, not listening to you beforehand.
- Had to find out about talking therapies myself
- Nurses having too much on their plate
- Long delays on the day of discharge (pharmacy/transport)
- Have to get a taxi – ambulance taxi, not being able to use bus lanes
- Relative appeared different on the day of discharge? Unsure why?
- Day was on other day than that? Due to emergency surgery – needed to arrange

- a care plan for person- Nobody was at home to support me.
- Gap in re-ablement starting to support me taken longer to recover.
- Hospital not listening. LA not listening or communicating my situation with each other.
- Was expected to ask for the service when at hospital- not by social worker discouraged me communication error. Nurses were good, medically brilliant. Hospital was fantastic.

### **Question 3- Carers have said they struggle to get information.**

- Carer champions in each practice
- Practices should be aware of the carers centre
- Don't always understand the difference between social and NHS responsibilities
- Don't always understand the different roles of people involved
- Carers are not involved in the MDT/discharge meetings
- Re-admissions because discharge has not gone well
- Don't always understand what the likes of Gateway is
- Chart of health professionals roles, different uniforms and what they do
- Don't understand what the likes of Gateway, single point of access, age uk, carers centre etc. do
- The 'KEY' could this not be used across the whole health and social care patch, so everybody involved in the care of the patient understands that they are looked after by a carer
- Lots of info out there but don't always know how to access it
- Roll out further
- Take concerns about daughter to GP
- GPs to tell PT about keys and appointments.
- Husband fell during the night- heavy man. Who do I call? Care Call different levels of care call. Level 1 emergency if nothing in place call the ambulance.
- Keep information up to date in GP practices
- More Paula's are required. Carer feels guilty if contact Paula and then contact again soon after as other issues has arisen.
- GP aware but needing to advise other Health Care Professional /not my remit
- St Oswald's use a holistic approach
- Lack of joined up approach- not looking at person as a whole.
- Knock on effect with the carer, raising complaints constantly.
- Fine with GP get admiral nurse (Age UK) GP referral
- Have followed up with GP
- Consumed with keeping practical tasks in household- difficult as getting older- missing out on goal parts? Home helps not atmosphere mentally not able to apply – depends on your own health – feeling guilty.
- CAMHS no signposting team GP- no communication from CAMHS to other teams had to do this myself
- Literature
- Didn't get key for carer from GP
- Long waiting lists when crisis hits
- Distressing to more reportative discussion around medications
- Link with talking therapies
- Sessions are improving , people are talking about the issues carers are facing

- More mental health support/ signposting
- Mental health and physical health services in the NHS talking to each other
- 6-7 GPs in surgeries not having a clue on my experiences
- Involved in aftercare
- Listen
- Involve from start from first referral
- Involve in care
- Information needs to be shared at the right time
- Point of readiness to share the information- but didn't have follow up around it.
- Relative had a diagnosis, but perhaps need to ensure carers are recognised as part of the process
- Recognise carers in their own right.
- Difficult to get diagnosis- but then lack of follow up around this

## **What can the health service professionals do to recognise support?**

### **Additional 3 keys points from the event**

1. Information on display at GP practices need to be up to date. One Carer had found discontinued services being advertised.  
The GP never has enough time to explain what's going on. Repeat prescriptions are difficult to process, signed up for online now.  
The consultant does not listen; they do not speak to other consultants to get the whole picture. EG neurologist does not speak to cardiologist, (different hospitals).  
Questions are never fully answered or understood. Specialist nurses don't have access to results or have the knowledge to discuss them. Feel unsupported and appointments have a huge gap between them at least 6 months.
2. Hospital discharge – people carers said that they had not been involved in discharge planning. Carers wanted to have an opportunity to speak alone and confidentiality to professionals.  
A and E at Cramlington were great. As were the paramedics
3. People are unaware of the carers register at the GP, and if they have been identified as being on it.  
Be able to point carers in the right direction. To understand or notice the sudden impact of becoming a carer. Look out for worrying signs of someone struggling to be a carer that's unsupported and new to the role.  
I picked up the purple key myself from reception without any guidance, after a visit to the GP with my husband. We had many appointments with our GP and this has never been mentioned.

## What are your experiences of hospital discharge? (RAG) Rating

Do you think healthcare providers and professionals can do better to support carers?

Red	4
Amber	3
Green	2

Carers have said they struggle to get information?

Do you think healthcare professionals recognise, support and sign post carers to the right services?

Red	5
Amber	6
Green	2

Do you think they know how to identify and support carers?

Red	4
Amber	6
Green	4