

Messages from carers

These are the summarised messages from carers at the 2004 Engaging carers conference

Messages to my local GP, community nurses and pharmacists

Use carers to train professionals.

GP: Have carers on practice committees.

Nurses: take the carer into your confidence, allow the carer to work jointly with the District nurse to compile vital nursing reports.

Doctors: Call in the long-term carer for periodic health checks and a chance to talk about their caring role; you are the gatekeeper.

Carers' key contact cards. Get them; give them to carers and those that support them.

GP Surgeries: have carers be identified, have a chat with them to get both their memories/experiences of the cared-for person but also to let the carer know what info/help/ services are available to them.

General practice needs flexibility – take carer's needs/requirements, difficulties into consideration.

Listen individually and collectively.

Primary care/ hospitals social services 'Active listening' to carers and liaison between services.

District nurses - remember that we will care full time for that use.

Well done, but continue - don't stop.

PCTS: in commissioning need to look at inequalities in mental health services.

Give qualified carers a card so they will be trusted.

To my pharmacist: train carers about drugs.

GPs; identify and support all carers, make compulsory with target issues.

GPs: you are key to identifying invisible carers.

Nurses: Learn your job well, e.g. incontinence pads, you need training support. Value carer input.

Pharmacists, please provide a consulting room.

Don't patronise patients or carers.

Sort out repeat prescriptions.

When things go wrong, welcome the learning opportunity.

Respect our expertise.

GPs / Primary care: identify all carers and see carer at least once a year.

GPs: inform, consult, identify, register, respect, refer/support all carers.

Talk to us - listen to us (carers) about our needs and experiences.

Involve carers as part of team on an equal basis.

Listen - don't make assumptions.

GP Surgeries: for mental health patients, have two GPs' opinions to ensure cared-for person gets the right care. This will help the carer by taking pressure off as care will be improved i.e. GP can see if medication is working if other GP is not monitoring.

Community Nurses: you must listen to carers as they know the patient best of all.

GP surgeries: for mental health patients ensure they see Doctors not locums!
Continuity of care helps carer.

PCTs: Set clear objectives and targets to GPs to identify all carers in each practice and see each carer at least once a year. Also reward GP's for meeting targets / objectives.

PCTs: set clear objectives and targets to hospitals and Mental Health hospitals to fully brief carers on diagnosis and medication.

PCTs: social services – need to look at searching date to impact service delivery.

Messages to my social services

Please make direct payments more available, and don't discriminate against people with dementia.

When things go wrong, welcome the opportunity to learn.

Social workers, please cooperate and collaborate with NHS (they can't do this alone.)

Social services need to become more flexible (24/7).

Be aware of carer and benefits.

Listen to carers! And learn....

Pay attention. Listen.

Social services, together with carers, teach the health service some of the skills you've picked up over the years - share experience with the health service.

Hospital/ social services, communicate with each other properly.

Communicate with the patient, communicate with the carer. (In my borough, I have usually found it necessary to provide the communication links myself.)

Integrate your IT with NHS so we don't repeat basic info endlessly.

Get more staff. (You're overworked but we need your help!)

Respect our expertise.

Social services implementation of care (and carers) assessments – aren't worth the paper they are written on.

Social services: keep carers informed and involved with users' care package.

Messages to my ambulance trust

Ambulance services, need for carer to accompany patient in ambulance – could be instrumental in saving the person's life.

Ambulance: Keep carer informed, where going – going where, when. Think carers.

When things go wrong, welcome the learning opportunity.

Joint working carer, ambulance and hospital.

Ambulances: appropriate assessment of needs/ individuals.

Ambulance: allow carers to go in ambulance with user.

Ambulance trust. Patient Voices.

Ambulance: don't make assumptions especially about mental health.

Ambulance trust: better information training given all around on "sectioning" process.

Ambulance trust: carers are often more able to do A & E handovers. That way important info is not lost.

Ambulance: you are brilliant.

Messages to my carers organisation

Set high standards so you're the obvious choice to support carers.

How many carers here today are NOT involved with a carer's centre or hospice?

Carer support: Working carer, 24 hour cover, BME – ethnic minorities, 'Hidden carers' young carers.

Hold your independence beyond price.

Must get better at marketing.

Find hidden carers.

Carers' groups, what happens to carers when their cared-for dies, reintroduction, training, etc.

Carer's organisation, use of outreach workshops in GP surgeries to inform about carers and care centres.

Carers support organisations, be accountable to the carers themselves rather than your funders, or resign.

Carer organisations not to act as gatekeepers but involve carers - not take their place on PCT committee etc.

Carers org – tell them to attend our meetings, don't always ask us to go to them for consultation.

As well as support and info, also 2-3 times a year (maybe) have sessions just for carers themselves, i.e. hand massage, aromatherapy, reflexology, etc.

You're doing a great job but don't let politics distract from meeting carer's basic needs.

One point of contact for all carer's orgs.

You are on the same side as the professionals, together we can achieve more.

Carer organisation: Alzheimer's society, thank you for being my life line.

Messages to my local hospital

Hospital: Your patients are people - not units - with loving carers who can help you.

Complaints procedure – patients can complain but carers can't.

Increase knowledge and understanding of carers' issues.

Invest in training (get involved).

Staff should offer training (for free) to carers to help them engage with the NHS.

Carers should be integral part of care team.

Health professionals in general. The only way that family centred care can be delivered is to involve the carers.

Listen to Carers! And learn....

Hospitals: Treat carers as part of care team - involve them in decisions rather than telling them.

Hospital: identify, register, respect, refer, support, inform, consult all carers.

Acknowledge that we are there (Carers) and have skills and abilities.

Staff should notice that 'vital spark' in carers and actively encourage them to engage - general appeals don't bring in the best people.

Listen and trust carers.

Local hospitals, we need comic/picture guidelines for people who can't use words.

When things go wrong, welcome the learning opportunity!

Listen, don't make assumptions.

Talk to carers! And listen.... and learn...

Local Hospital – make all your words disability friendly – e.g. incontinence pads, hoists, assistance with feeding, make patient notes available across authority in emergency admissions.

Recognise that carers' expertise can exceed that of a professional in some areas.

Hospital: inform all carers of diagnosis/ medication for the cared for.

Stop hiding behind confidentiality and data protection act. (These are issues, but so often they're used as an excuse to avoid involving carers)

Hospital, involve carers at all stages, and identifying carers must be a priority.

Involve carers directly, not care workers.

Little things count – picking up info through short simple questionnaires and acting upon it is as good as huge consultation exercises.

Identify carer from beginning.

Standard protocols from carer throughout.

Messages to my mental health trust

Inform carers if coming home to leave change of medication, housing, etc.

MH systems: carer involvement throughout! Handovers to/ from carers!

Where things go wrong, welcome the learning opportunity!

Carers should be integral part of care team.

Carers' key contacts cards: get them, and give them to carers and those that support them.

Listen to carers! And learn...

DH: When things go wrong in hospital, nurses have bell to ring, carer has none.

Mental Health Trust/social services: improve your recruitment/ training procedures. Three months is too short a probationary period, good training by carers should be compulsory and employers should be required to attend sessions. One person should be responsible for every patient – buck passing happens all the time at the moment.

Recognising boundaries re info and confidentiality.

All trusts: remember the carers need to work in partnership to meet individual's needs.

Realistic use of confidentiality and info sharing.

Inform all carers of diagnosis and medication for cared-for person.

Messages to NPfIT

Better use of IT/Communications between patients/ carers/ GPs/ hospitals etc., e.g. accepting emails and acting without needing signed letter first.

IT – share 'top sheet' info amongst agencies so we don't endlessly repeat basic info!

NPfIT: centralise info from carers to enable all departments to access.

NPfIT: section for info to be given to carers.

To all: recognise carers and their values.

IT: full involvement of carers through out NPfIT development.

Value those whose knowledge can inform the services you seek to 'design' and deliver to patients and carers.

IT – 'Trigger' points in system, which lead to carer support.

National programme info link whole picture.

NPfIT: when, how will patients and carers be trained?

'Patient voices.'

NPfIT: will carers have input how 'health space' is developed and used?

Messages to the DOH

Dept of Health: training of professionals to learn how to 'listen and learn' from carers and to teach them how to value carers' role and knowledge.

Carers sometimes know more than the 'professionals'.

Department of Health, make money available for carers' issues.

DOH: carers must assess the performance of professionals – in annual appraisals, how they communicate with us Etc.

Carers czar.

Professional help can be TOO speedy and assume they have it sorted and don't think carer knows. Statutory orgs should set up independent orgs for carers (Not a dept with in NHS).

DOH: ban tick-box assessments, stop defining 'nursing care' by who gives it, encourage specialist nurses in the community as consultants to district nurses and others e.g. admiral nurses for dementia.

Put in obligation on authorities to inform carers (and penalties if they don't).

Research on carers' needs.

Do joined-up thinking!

'Patient voices'

Everyone, move from – patient-centred focus to relation centred i.e. patient and carers (ref: Prof. Mark Nolan)

Social services – listen to carers.

Carers' champion in DOH.

Advocacy nationwide.

Better health closer to home carers.

Dept of Health: every policy includes carers.

NHS: more opportunities for carers to be involved in training professionals.

DOH: set clear targets/ objectives to PCT's to address carer's key issues.

DOH: where are you carer's leads?

Strategic Health Authority: set clear targets and objectives to PCTs to address carers issues.

Educate! (Re-educate?)

Where things go wrong, welcome the learning opportunity.

Fund voluntary orgs properly if they're doing a good job (don't reinvent the wheel).

Carers' voluntary organisation representatives involved in planning, strategy and parcelling out of grants.

Voluntary organisations shouldn't be constrained by their NHS funding – funding should be given to let them operate independently.

Respect our expertise.

Improve equity of provision to carers according to need, not according to who shouts loudest.

All risk assessments to include carers (and users!).

More research into carer's health and safety.

DOH: we need a carer Czar ASAP.

Try to see through patients' and carers' eyes.

DOH: accreditation of our experience (NVQs), basic standards of support for carers to be equalised nationally.

Messages to the government

Government: revise policies to include role of the carer. For with a burgeoning population and fewer beds, without carers' input you are sitting on a time bomb. Remember grey vote power!

Government: Carers' allowance is totally inadequate.

Government/Dept of Health: be more flexible when designing services for mentally ill by considering research showing effectiveness of approaches other than the medical model. The loneliness and misery of thousands of mentally ill, left alone to their own devices is a national scandal.

Government/Dept of Health: Stop making it so difficult for carers' voice to be heard and registered. Often voluntary sector groups who manage/ coordinate carer or user groups have a vested interest in shutting up carers when complaining about services because they themselves are funded by dept. of health.

Government: deal with carers, not development workers.

Real information and support, not rhetoric.

Users, carers, care workers.

Gov, etc. etc. clarification of 'carer' title role.

Government: more money, more respect, more recognition or we won't vote.

Government: budgets, Be Bold? Carer or patient-held budgets? (Not direct payments.)

Govt/DH/Healthcare: Measures dictate behaviour, need for measure that will influence professionals etc. need to develop this with carers.

Govt ministers should know what they're talking about before going on radio broadcasts.

To the government, I am doing your job without pay. Some help would be an improvement.

Walk in carers' shoes.

When things go wrong, welcome the learning opportunity.

Include the word 'carer' in documents and acknowledge their contribution.

Government: set clear targets/ objection to PCT's to address carer's key issues.

Definition of carers put on form to reinforce that 'carers do caring for free'

Government: Single carer's assessments, to become part of care standards, money to be made available to local trust to do these.

Decision makers should understand the needs of carers. Government should address the needs of carers by law. This would come down to the local agency to act upon.

Carer's votes count. Win them!

What does it take to make people realise a carer is the next best person to a hospital nurse?

Policy is ok but results are to come. Enforce results.

Health professionals are more powerful than politicians (In ignoring carers.)

Government: Make sure carers' legislation has teeth.

Listen to and value the experience of those who can inform the services you serve to 'design' and deliver: patients and carers!

Government: confidentiality may be an issue for the patients, but as a carer, I have no problem saying my view, so why does the process discount carer's view because it is confidential? We're giving information, not talking.

Listen to carers! And learn...

Government named inclusion of 'Carer' in legislation/ strategic planning.