



HEALTHCARE RIGHTS, COMMUNICATION & PATIENT SAFETY

John's Campaign

Family carers as partners in care
when their support is wanted and needed

The key idea

John's Campaign promotes welcoming family carers as partners in care, rather than treating them simply as visitors. Their knowledge can support communication, reassurance and continuity — while the person receiving care remains central and the carer's involvement is a choice, not a duty.

What is John's Campaign?

John's Campaign began in 2014 after the hospital experience of Dr John Gerrard, who was living with Alzheimer's disease. It campaigns for people with dementia, and people with other disabilities or individual needs, to be supported by the family carers or other essential supporters they rely on when receiving health or social care.

In everyday language

Someone who knows a person well may be much more than a visitor. They may understand how the person communicates, what reassures them, what is normal for them and how they show pain, fear, hunger or distress.

Why can a familiar carer matter in hospital?

Hospital can be unfamiliar and disorientating, particularly for a person living with dementia, cognitive impairment or complex support needs. A familiar person may provide reassurance, help staff understand communication and routines, support eating and drinking where appropriate, notice changes from the person's usual presentation and contribute useful information to care and discharge planning.

A partner in care, not additional staff

The campaign's principle is that carers should be welcomed as partners where their involvement benefits the person. This does not transfer nursing or professional responsibilities to them. Carers are there to nurture, not to nurse.

Key distinction

A family carer has a right to offer their support, not a duty to provide unpaid care in hospital. A hospital admission may also be a time when a carer needs rest. Services should not make safe care dependent on a family member being present.

Who counts as a family carer?

The important relationship is not necessarily biological family. A spouse, partner, adult child, close friend, personal assistant or another person may be the individual the patient relies on for essential emotional or practical support. The person's own wishes should remain central.

Beyond normal visiting hours

A central principle of John's Campaign is that essential carers should be able to be with the person when they are needed, rather than being restricted automatically to ordinary visiting hours. Depending on individual need and local arrangements, this can include extended access or staying overnight.

What this might look like

A person with dementia becomes frightened and stops eating when their partner leaves in the evening. With the person's agreement, the ward enables the partner to remain outside ordinary visiting hours, while staff continue to hold responsibility for clinical and nursing care.

The person's wishes still matter

Carer involvement should not override the person receiving care. Where the person can express their wishes, staff should ask who they want involved and how. Information sharing, consent and confidentiality still matter. Where a person lacks capacity for a particular decision, the relevant Mental Capacity Act framework should be followed.

Information carers can contribute

Someone who knows the person well may be able to explain communication, routines, food and drink preferences, mobility, sleep, sensory needs, signs of pain or illness, distress triggers and what helps. They may also notice subtle changes that are difficult to recognise from a short clinical encounter.

Important clinical point

Information from a carer can be clinically valuable, but it should complement rather than replace assessment of the patient. Staff should listen to both the person and those who know them well, while retaining professional responsibility for assessment and treatment.

Communication and continuity

Familiar supporters can help healthcare teams understand communication that is highly individual. They may know what particular gestures, sounds, facial expressions or behaviour mean for that person. This can be especially important when illness, pain, delirium or an unfamiliar environment changes how someone communicates.

Eating, drinking and personal routines

Some carers may choose to support familiar mealtime or personal routines if the person wants this and it is safe. Staff should still assess clinical needs, including swallowing, nutrition, hydration and mobility, and should not assume that a carer will take over these responsibilities.

Involvement in care and discharge planning

Carers can hold important information about what support is realistically available at home, changes in the person's function and what may be needed after discharge. Involving them early can help identify practical issues before the person leaves hospital.

For professionals

Ask rather than assume: Who is important to this person? What support do they usually provide? Does the person want them involved? What knowledge can they contribute? What support does the carer themselves need?

If a service has made a John's Campaign pledge

Hospitals, care homes and other services can pledge to the campaign. A pledge signals a commitment to welcoming family carers as partners in care. Local arrangements can differ, so people can check the campaign's participant information or ask the service about its carers policy, carer passport and flexible-access arrangements.

John's Campaign and wider rights

John's Campaign is a campaign and practice commitment rather than a single standalone law. However, carer involvement can overlap with other legal and professional duties. For example, a disabled person may require a familiar supporter as a reasonable adjustment under the Equality Act 2010, while person-centred care must reflect individual needs, preferences and relevant consent or capacity requirements.

Important to know

A service does not need to use the words 'John's Campaign' for a person to need carer support. Ask about individual needs, reasonable adjustments, the local carers policy and how essential supporters can be involved.

If access is being restricted

Explain that the person relies on you for essential support and describe the specific need rather than only asking for longer visiting. Ask to speak with the nurse in charge, dementia or learning-disability team, carers lead or patient-experience service where available. If presence is needed as a disability-related adjustment, make that need explicit.

Supporting the carer too

Partnership should include recognising that carers have needs of their own. They may be exhausted, worried or unable to remain for long periods. Good practice means enabling involvement without making the carer responsible for filling gaps in staffing or clinical care.

Practical check

Who does the person want involved? What does that supporter know that could improve care? Is access based on the person's needs rather than routine visiting rules? Are consent, confidentiality and capacity handled appropriately? Is the carer welcomed without being expected to become unpaid ward staff?

References & Further Resources

John's Campaign operates across the UK and across different care settings. Local policies and arrangements vary, so the individual service should also be asked about its current carers and visiting arrangements.

John's Campaign	Current information about the campaign's principles, family-carer guidance, acute care work and participating organisations.
NHS England - John's Campaign	NHS England has supported enabling carers of people with dementia to remain with them in hospital when their support is needed.
NHS England - RightCare dementia scenario	A current NHS England dementia pathway scenario illustrates a family carer staying with a person in hospital and being included in care and discharge planning.
Carers UK	Information and advice for unpaid carers, including support, rights, work and finances.
Carers Trust	Support for unpaid carers and local carer organisations across the UK, including practical and emotional support.

How to use these resources

Use John's Campaign for current campaign principles and participant information. For a specific hospital or care setting, also check its own carers, visiting and reasonable-adjustment policies. Wider legal questions may depend on the person's circumstances, consent and capacity, disability-related needs and the care setting.