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# Your guide

## The new Carer Passport in hospitals



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# About this guide

The aim of this toolkit is to provide you with the know-how, insight and expertise to build your own Carer Passport scheme within a hospital setting – to provide a clear offer to carers, as well as links to advice and information and provide a mechanism to improve identification and support.

There is a clear recognition that Carer Passport schemes are often owned and developed locally, or by an employer, to suit their needs. We use the experience and knowledge from key leaders who have developed a Carer Passport locally as well as the experience of carers to provide all the insight and content needed to get a scheme going.

The work is being carried out by Carers UK and Carers Trust with funding from the Department of Health and Social Care with the aim of increasing the number of Carer Passport schemes in England which seek to support carers. It is part of our broader work and drive to build Carer Friendly Communities.

#### What benefits can a Carer Passport bring?

Experience locally shows that a Carer Passport schemes can:

- Aid identification and support of carers.
- Raise awareness of caring.
- Provide a concrete, easily understandable offer of support.
- Provide a mechanism that makes carers feel valued.
- · Provide help/assistance to managers or key professionals.
- Provide a short-cut to knowing what support is needed, without having to ask lots of questions.
- Help in local discussions and support.

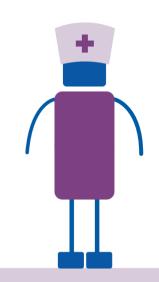
#### Where are Carer Passports currently used?

- Employers use a Carer Passport to support carers in the workplace.
- Hospitals use a Carer Passport and similar schemes to identify, recognise and support carers on specific wards or across the whole hospital.
- In a local community a Carer Passport scheme looks at whole a range of support and information as well as discounts for local services. They are often a popular way of engaging with carers who might not otherwise ask for help.
- Schools, colleges and universities have a Carer Passport to support pupils and students who might need additional information and advice or adjustments because they are caring.

### **Carer Passport guide**:

# Hospitals

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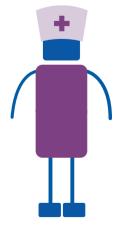
### Key facts about carers

#### What is a carer?

- A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.
- A young carer is someone under 18 who helps look after someone in their family, or a friend, who is ill, disabled or misuses drugs or alcohol.
- Young adult carers are young people aged 16–25 who care, unpaid, for a family member or friend with an illness or disability, mental health condition or an addiction.
- Our health and social care services rely heavily on support provided by carers, with the contribution they make currently estimated to be worth £132 billion a year.
- The Government's mandate to NHS England (2017/18) sets out a commitment to identify and support carers.
- In 2014, NHS England published its Commitment to Carers, which includes raising the profile of carers, person-centred coordinated care, and education and training.
- Over a third (36%) of carers rated hospitals as carer friendly, whilst almost a quarter (24%) said their hospital was not carer friendly and 13% found their hospital the least carer friendly service in their community.<sup>1</sup>
- Almost a quarter (21%) of carers said their hospital does not recognise their caring role.<sup>2</sup>
- Six out of ten carers (61%) said the lack of support for them had a negative impact on their health.<sup>3</sup>

# **£132**bn

The estimated contribution that unpaid carers to health and social care services each year



2 Building Carer Friendly Communities, Carers Week, 2016

<sup>1</sup> Building Carer Friendly Communities, Carers Week, 2015

<sup>3</sup> Building Carer Friendly Communities, Carers Week, 2015

# What is a Carer Passport in a hospital?

#### Identification and recognition

A Carer Passport in a hospital is a simple tool which identifies someone as being in a caring role for one of the hospital's patients. Hospitals can be where the caring journey begins or intensifies, following a stroke, diagnosis of a serious illness, such as cancer, or the birth of a child with a disability.

Encouraging carers to self-identify can be one of the main challenges in supporting them. Information and advice is often hard to find and navigate, with a confusing pathway between the NHS, social care and a complex social security system. Providing support benefits the carer directly, the person they are caring for, and has clear benefits for health professionals as they work towards the best outcomes for their patients.

The Passport will usually take the form of a card, badge or booklet which is easily recognised by staff, and which names the person as a carer. It should contain the details of the Carer Support Worker or Carers Lead where there is one, and if not, should name a nominated member of staff such as a Dementia Lead or Head Nurse.

#### Involvement

It should explain what the carer can expect from hospital staff (the 'offer' to them), in accordance with the NHS Constitution commitment to carers being involved and consulted in the care and treatment of their family member or friend. This may include staff explaining treatments to the carer, and the carer being involved in planning the discharge of the patient. Information supporting the Passport should also contain details of any financial concessions offered to carers, as well as an offer or link to locally tailored information including Social Services contacts, information on Carers Assessments, and organisations which can provide further advice and information.

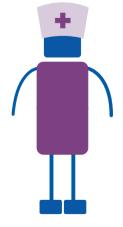
A Carer Passport scheme enables hospitals to become more aware of what it means to support someone who has identified themselves as a carer, and to accept them as an expert to involve in decision-making.

With discharge planning, for example, this needs to involve carers from the start. Staff need to be absolutely clear about the situation at home and what carers can expect from the discharge (who is doing what, when, and what to do if things don't go ahead as planned). They provide recognition and respect for the carer as a partner in care.

# 66

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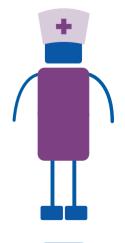


#### **Practical help**

Passports in hospitals also tend to include offers to practically and financially assist carers, and these are welcomed. This includes concessions on the cost of hospital car parking (note that the Government updated its guidance to NHS Trusts in 2015 to include this expectation) and the offer of discounts in the staff canteen, inclusion in refreshments on the ward, access to washing facilities, etc.

It is not uncommon, for example, for carers to spend £100 per week on hospital parking when their total Carer's Allowance is just £62 per week (2016/17 rates). These offers are of practical and financial help, but also send a clear message to carers that their role is acknowledged and valued.

Involving carers through all aspects of treatment and care and offering specific concessions to carers is effectively a way of saying to carers 'you are welcome and have a legitimate right to be here'.



### What examples are there?

Many NHS Trusts are now doing more to value carers in the healthcare setting, and there are an exciting number of initiatives around carers.

Models are in place in many hospitals in England. These help to identify carers at an early stage (including new carers who need support from the start), and give carers confidence about what they can expect from hospital staff and that their caring role is recognised. They benefit from the carer's expertise on treatment and care issues, and ensure better understanding and coordination between the patient, carer and staff. The initiative will be implemented within the context of hospital guidelines around carers and the NHS Constitution.

## Central Manchester University Hospitals NHS Foundation Trust

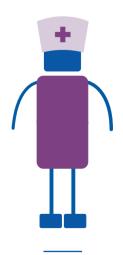
During a pilot at the Central Manchester University Hospitals NHS Foundation Trust, which trialled open visiting as part of a Carer Passport, nearly two thirds (59%) of staff felt it had improved communication between staff, patients and their relatives. Prior to the pilot, only 23.5% of carers and patients thought that staff were available to discuss care and treatment, which rose to 100% at the end of the pilot. The pilot also saw a reduction in the number of falls compared to the same time in the previous year, which the Ward Manager felt was contributed to by open visiting.

#### John's Campaign

John's Campaign has resulted in a drive to get hospitals and all residential care settings to sign up and implement measures so that carers of patients living with dementia can have the right to stay with them in hospital if they wish and to be treated as partners in care.

Health service experts consulted as part of this project report the impact of this at local level. This was included as one of 29 indicators for the NHS England's Commissioning for Quality and Innovation (CQUIN) payment framework in 2016/17.

The expectation is that this would see a wider take-up of the principles which underpin John's Campaign, whereby hospitals will be implementing a policy on welcoming carers and family members according to patient need and not restricted by visiting hours. These policies can be extended to all carers in different settings across the UK.



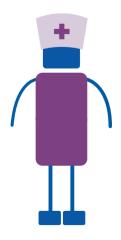
#### Surrey and Sussex NHS Healthcare Trust

In Surrey, through the use of Carer Prescriptions, Clinical Commissioning Groups are already implementing a joined-up approach between hospitals, GP practices and other healthcare services. Again this has been given extra leverage by the NHS England Commitment to Carers and the Carers Memorandum of Understanding toolkit. The Carer Prescription is a mechanism for identifying and referring carers for support. This started at primary care level in response to GP interest in offering more to carers (including referral for carers breaks). It was soon extended more widely and every provider in Surrey is now signed up. Once completed, a copy of the prescription is added to the patient notes – though some Trusts simply use a Carer Friendly sticker in recognition of the carer role.

This initiative sits alongside the use of Carer Passports in Surrey's hospitals, which are described as both 'permission to be involved in care' and an acknowledgement of the value of carers by providing specific concessions. The Passport is seen as fostering a culture of Carer Friendly practices in local hospitals, and a useful tool for hospital staff to recognise the Partnerships In Care model. In Surrey and Sussex NHS Healthcare Trust, the Passport is used throughout the Trust and aimed at in-patients. The wider package for the Passport includes instructions to staff (with a flowchart of what staff can do) and a poster signposting carers to Carers Support. Offers include staff discounts in the restaurant, use of refreshment rounds on the wards, and specific car parking arrangements. The Passport 'sanctions carers to get involved in all aspects of the patient's time in hospital', including involvement in washing, dressing and feeding the patient, attending team meetings and providing support for investigations.

#### **Pinderfields Hospital**

At Pinderfields Hospital, part of Mid Yorkshire Hospitals NHS Trust, a Carer Passport was introduced following feedback from carers of patients living with dementia, and recognition that involving carers in dementia patient care eases the anxiety felt by those living with the condition in a busy hospital setting. One of the most innovative features of the Passport is a special password which allows nurses to share detailed information about a patient over the phone. The hospital also built six family support suites to enable families to spend the night with their loved one. The Carer Passport has been given out to over 900 carers, with positive outcomes reported including carers feeling valued and able to communicate the patient's needs to hospital staff.



### What difference does it make?



#### **To carers?**

"When my mum-in-law was in hospital, I felt that I was being overlooked by the staff and I approached the patients help system. I was then told about the Passport. Using it meant I could then go into the ward outside of visiting hours, so was there when doctors came round.

I was also able to help with her personal care. It was extremely useful, but a shame that I only found out about it when I was distressed about how I was being side-lined."

– Carer

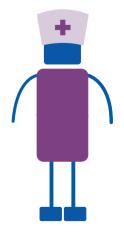
#### **To employers?**

"Carer Passports ensure our patients and their carers have a seamless journey, from admission to discharge. It creates an identify which allows carers to be part of care."

- Deputy Director of Nursing, Lister Hospital

"This initiative has benefited in improved communication and access to consultants. Carers, family and friends are the experts and decision makers.""

- Divisional Chief Nurse, Medicine, Surrey and Sussex Healthcare NHS Trust





# Introducing a Carer Passport scheme in hospitals

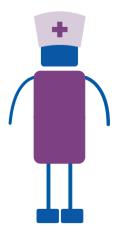
#### The benefits and business case

Many carers currently struggle to have their role recognised by health and care professionals. This has a negative impact on the patient, but also on the carer's own health and wellbeing, thus resulting in increased need for health service interventions. While there are a number of Carer Friendly initiatives across the NHS, there is little uniformity and support to carers can vary enormously. The Carer Passport can focus and articulate the support offer. Once this support is in place, it has clear benefit for carers, patients, staff and the NHS itself.

Carers will be better supported at an earlier stage, with positive consequences for their health, wellbeing and financial security. They will feel confident about what they can expect from hospital staff and more fully informed about what help is available. This is also to the benefit of patients, who have the expertise of their carer informing the treatment and care they receive, and better understanding and coordination between hospital staff and families. The practical and financial concessions often offered through the Passport (eg. hospital parking and staff canteen discounts, inclusion in refreshments on the ward) also serve as an important acknowledgement of the hardship often created when someone becomes a carer. The parking concession is now Government expectation in its guidance to NHS Trusts.

The part played by a patient's carer on the ward can be of significant benefit to staff. For example, the carer of a patient with Alzheimer's may be the one person who knows what food they will eat and can encourage them to eat it. Through offering flexible visiting times to carers, this can mean a patient eats their meals and doesn't become malnourished. While this hands-on support should not be assumed, and should not replace the input of nursing and other staff, it can be enormously beneficial to the patient and something which the carer is willing to do. Carers report staff saying that this help relieves the pressure on them, even saving on their budget.

For many carers, the Passport can also help create the opportunity to be involved and consulted in securing the right treatment and care for their loved ones. While the involvement of carers is sometimes questioned by staff, there are clear benefits to it happening. A carer's knowledge and experience means they can often add important information regarding the patient, including what happens when the patient is at home and the side-effects of treatment. For example, Involving a carer in decisions about drug changes can be hugely beneficial

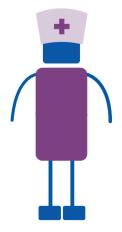


in gaining an overview of the impact of past changes. The Passport is also an acknowledgement that the carer is there to support the patient while in hospital but, unlike the hospital staff, their role also continues when they get home. This increases the chances of a successful return home for the patient, potentially reducing hospital readmissions.

At Lister Hospital in Hertfordshire, the benefits of their existing Passport scheme are clear. Reaching them is a priority, with this shaping the way in which the scheme is delivered. 'Keeping it simple' is the mantra, with carers issued with a bright yellow badge on a yellow lanyard which they can wear throughout the hospital. They are not named on the card, and can pass it to another family member where the caring role is being shared. The badge makes them easily recognisable as a carer to ward staff, and in the canteen and pharmacy where it entitles them to discounts. In the first 6 months of 2017, 135 carers were identified for the first time.

One of the key benefits of the Lister scheme is reported to be the culture change which it has brought about on the wards. Carers now have 24 hour access for visiting if appropriate and this is credited with contributing to more open communications with staff, less of a 'grid-lock' at peak visiting times, less staff time spent on phones, and a 'generally calmer atmosphere' which is widely welcomed. There is also early evidence of reduced falls when carers are present, with one of the scheme's pilot wards reporting 92 days of no falls. This is one of many initiatives introduced to reduce falls. Staff also see other benefits for patients, including improved eating and drinking, and the stimulation provided by the company of a loved one. A new computer system in the hospital help identify and share information about patients and carers, and should enable more data gathering around the differences made by the presence of carers.

Another scheme, delivered by North Bristol NHS Trust and University Hospitals Bristol NHS Foundation Trust presents patients and carers with a Carers Charter signed by Chief Executives, the Director of Nursing and Chief Nurse. On admission, a patient is asked whether they have someone who supports them. If they do, staff will speak to the carer and offer to make a referral to the Hospital Liaison Worker. A conversation also takes place to see if the carer would like to be involved in providing care for the patient while in hospital. Carers are given a carers lanyard enabling open visiting, an access card enabling entry to the staff restaurant for a hot meal, and complimentary car parking.



Nationally the value of such schemes has been calculated using Social Return on Investment (SROI) methodology and found to save the equivalent of £3.6million a year, including £239,000 in health services costs avoided. These gains have been attributed as £1.9m for the state and £1.7m for individuals.

#### **Elements of success**

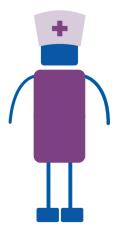
Good practice is often new and evolving, but there are some common themes.

A Passport can enable a conversation, its very existence providing a practical prompt if you like. It needs to be a conversation which is careful in its use of language as carers and those they care for don't necessarily label themselves and their situation in this way. But time and again, carers report the importance of open communications with them. They welcome real clarity about what to expect at what can be a difficult and stressful time, and an avoidance of over-complex and technical language to discuss (for example) discharge arrangements. Access to face-to-face, knowledgeable and calm support is also important – the chance to actually speak to someone who can give practical advice. It may be provided in a more informal setting, such as a drop-in cafe for carers. This ongoing dialogue is essential. Carers' circumstances will change over time, and the use of the Passport needs to embrace this.

At their most effective, Carer Passports are delivered as part of a package of Carer Friendly practices. These practices become a thread running through the hospital setting, which normalise the role of carers.

Hospital-wide communications should ensure that all staff are aware of these policies and practices, and how to use them. Passports are often championed by Carers Leads, with evidence that these roles are now being funded by a small number of Clinical Commissioning Groups in some hospitals. At Board level, there could be a Carers Lead, in the same way that they exist within local authorities. So where the Passport and other carer initiatives are being championed within a hospital, they are proactively offered to carers by hospital staff who understand their purpose and value.

Health professionals should consider the whole family when identifying carers, recognising that children and young people may also undertake caring responsibilities. Young carers have specific needs as a vulnerable group. These include communications which are clearly aimed at them, availability of appointments to support their attendance at school or college, professionals being aware of them as a 'hidden' group, and



the importance of recognising that they should be considered and consulted with regard to decision making. The approaches which are right for adult carers are not always appropriate for young carers.

Where Passports work effectively, they embrace Partnerships In Care principles, fostering the Carer Friendly practices of identifying, engaging and involving. The aims and principles of the Carer Passport in different hospitals across an NHS Trust will be similar, but the delivery mechanisms may differ. Where there is good practice in place, each hospital is adapting the Passport for its own purposes informed by an existing model or template which they have accessed.

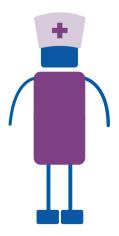
#### **Any challenges**

In hospitals, the Passport clearly needs to be promoted and offered consistently across all wards. So while it may be effectively championed by dementia nurses and patient experience staff, its reach needs to be wider. It should be seen as an issue for nurses, but also for administrative staff, therapists, doctors, clinicians, and for there to be management sign-up through governance. With hospitals affected by the use of agency and temporary staff, getting the message out there in a consistent way can be a challenge.

In terms of implementation and development, there is recognition that the systems are often not in place to record the take-up of Passports in hospitals, and to monitor how they are being used. Once a Carer Passport is completed by a carer, is it copied and filed? This may be unlikely because patient records are held, but not usually carer records. This raises a number of questions, including how to measure effectiveness, and if the reach and benefits to carers is fully known.

There are often barriers to young carers getting support within the NHS, partly through staff uncertainty about how to respond to them, including concerns about safeguarding and neglect. As a result, progress in this area is slow. In Surrey, a phased approach is being taken, starting in the community (eg. with a push for GPs to register young carers) and building to a planned Young Carers Pledge for hospitals. If this is indicative of what is happening elsewhere, the Carer Passport is unlikely to reach young carers in hospitals for some time, and yet they need to access support as much as adult carers do.

With Carer Passports increasingly recognised as a useful tool for supporting carers, there is the risk that they are developed in a number of different sectors within one community. A strategic, joinedup approach is required, as with the shaping of all Carer



Friendly policies and practices. There may be some hesitation around the cost implications of taking a 'whole systems' approach – or of an offer which reaches a large and loosely defined number of individuals. Hospitals need to be clear about definitions, the offer they are making, and how they will resource it.

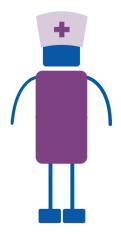
The majority of healthcare happens outside hospitals, and this needs to be acknowledged in improving support to carers via a model such as a Passport. If Carer Passports are to be part of a wider approach to delivering Carer Friendly practices, they become 'one tool in the box'. As such, the Passport is one mechanism of many and there needs to be a wider action plan connecting health and social care providers.

Finally, there may be a perception amongst NHS staff that an initiative such as this will lead to an increased workload. The benefits of Passports should be presented (based on experiences elsewhere), captured as they unfold, and clearly communicated to staff. Just some of the benefits we are already aware of include reduced hardship for carers and those they care for, smoother discharge and lower readmission levels.

#### **Promoting the Carer Passport in hospitals**

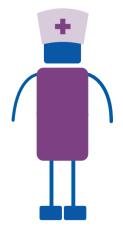
Within hospitals themselves, Carer Passports need to be promoted and offered consistently across all wards. One carer has described in detail the difficulties she faced when she attempted to mention her husband's long-term mental health needs to ward staff. She was treated with hostility and repeatedly had to justify her presence. The hospital had a carers policy, but staff would not recognise it. A Passport could have made a difference here, but the carer acknowledges that it could simply have been met with annoyance by staff if its purpose was not fully understood and embraced.

At Lister hospital, the scheme is promoted to all staff on the wards, to staff and visitors via an education stand staffed in public areas, through local carers organisations and Carer Champions in GP surgeries, and via local libraries. It is delivered by the Trust's designated Carers Lead, who is line managed by the Deputy Director of Nursing and has the active support of senior staff across the hospital. When championed at the highest levels of the hospital, staff are aware that this is the right thing for patients and their carers. The wider benefits of such a scheme are that they enable a shaping of services which respond to the needs of the patient and carer, improve their experiences, and reflect the Trust's values and NHS Constitution. This championing – from ward to Board – can make a real difference here.



So carers, and Carer Passports, need to be given status within the hospital setting. The policy to embed the use of Passports needs to be in place, with high levels of staff awareness of it, and training provided to ensure its effective implementation. Carers need to see the Passport more proactively promoted in hospitals, with clearer communications and information available. They report that it is of value once they have it, but that it sometimes takes a while to be offered.

Carers often acknowledge that a Passport will be most effective when it is used across the range of health and social care settings. For this to work, such schemes need to be introduced with the formal support and promotion from these statutory agencies.

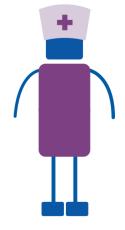


#### In conclusion

A Carer Passport within a hospital setting can be a useful tool to promote the safety of employees, engagement with carers and development of a truly inclusive organisation.

Each hospital can, in partnership with carers, plan and execute their Passports with creativity to meet the needs of their unique client base. A Carer Passport scheme can be an opportunity for hospitals to integrate the work they do with carers into their everyday practices and seeks better outcomes for patients, their carers and families.

If you would like to view templates, good practice examples and get some ideas about developing your own Carers Passport, go to www.carerpassport.uk





### Appendix What might a Carer Passport offer?

#### **Resources and templates**

- >>> Leaflet to explain the scheme
- >>> Poster to promote the scheme
- >>> ID card template
- >>> Going Ahead summary





Find out more and access resources at:

carerpassport.uk