

The Benefits of being 'Gold Patients'

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With the ageing population, and more people living longer with underlying health conditions or co-morbidities, more are likely to need extra supportive care earlier in the final years of life. So, the more proactive, anticipatory approach that GSF recommends and enables across health and social care settings, with early identification of people who might possibly die in the next year, seems even more important.

This is what GSF aims to do, helping teams use a systematic, consistent quality improvement approach that helps earlier more person-centred care, enabling better coordination and reducing avoidable hospital admissions, so that more can live out their final chapter of life well, and die well in the place and manner of their choosing. GSF provides a simple three-step pathway - identify, assess and plan - along with the tools and resources necessary to make this a reality on the ground, and early identification of patients considered to be in the last year of life, where this is possible, is seen as the starting point and the foundation for improved end of life care.

Many teams over the years using GSF have called these identified people their **GSF or 'gold patients'**, and many try in their own areas to develop some key benefits for their gold patients, offering advance care planning discussions to all and supporting better communication and coordination of good care to enable 'gold standard care'. Benefits of being identified as a 'gold' patient in different settings are explored as part of GSF training and are found to outweigh any possible negatives of the sometimes difficult conversations required, as long as people are sensitive in offering such discussions and aware of the choice of denial as a coping mechanism for some.

Benefits in general of the early identification of Gold patients include a sense of empowerment of people, more open discussions through advance care planning discussions with families and carers, greater awareness by family and carers so earlier preparation, better proactive support mobilised by care providers, triggering proactive care and anticipatory prescribing. From the person's viewpoint, hearing the message from doctors 'sorry, but there's nothing more we can do for you' might imply they are left to manage alone, are 'on the scrap heap' and apparently rejected by health providers, whereas ensuring they have gold standard care and are gold patients is reassuring and positive statement of support that is a relief to people and their families.

Some more specific tasks triggered by being a gold patient include some prioritisation of care e.g. special GP appointments reserved for gold patients, focussed GP visits for care homes, quick access to services such as prescriptions, gold home packs with useful information, rapid discharge for hospital patients, open visiting, free car parking etc. Preferences both big and small would be more likely to be discussed and respected, such as preferred place of care, and other dignity-enhancing details of care preferences in the final days such as music played, not dying alone and even gin mouth washes. And for some areas, development of better integrated cross boundary care, with the needs and preferences of identified GSF or gold patients shared across the wider area through electronic systems, and for some, helplines such as Airedale's Gold line developed - more details of such examples are included below.

Feedback from many such gold patients and their families has largely been positive, with many feeling empowered and listened to, rather than feeling that there is nothing more that can be done for them. Many said that, although they cannot prevent the inevitable in the end, they feel reassured that they are more likely to receive top quality care in line with their wishes. By putting people at the heart of everything and giving them a sense of control over their care, this can improve outcomes for them and their carers, reducing hospital crises towards the end as well as relieving pressure on services.

So although some might find this concept of gold patients rather odd and counter-intuitive, many others found that such earlier identification and aspiration to the best possible 'gold standard' care for GSF or gold patients, can lead to a better quality of life lived, more meaningful discussions with those close to them, deeper emotional and spiritual harmony, and practical elements such as better coordinated care, more dying where they chose and better prepared families with greater satisfaction with the care provided for those bereaved.

Some Specific Examples of use of GSF and identifying Gold patients in wider geographical areas - also see <http://www.goldstandardsframework.org.uk/cross-boundary-care-training> and the Frontrunners flyers for each area <http://www.goldstandardsframework.org.uk/evidence:->

Southport and Ormskirk Hospitals NHS Trust was among the first acute hospitals to develop the concept of gold patients, driven by a desire to provide more coordinated, personalised care. This helps generalists make that initial identification on the ward and have conversations with the patient about what it means to be a GSF or gold patient and giving them a 'gold card'. They will contact the patient's GP and get them to on their practice GSF registers and support better coordination of care. Dr Karen Groves, Palliative Care Consultant at Southport and Ormskirk says: "Everybody in the hospital and across all health settings in the area knows that this means that there is more to this patient than meets the eye and that they need to treat them with extra special care. We are trying to ease their way through the system and make sure no one falls through the cracks and do our best to get them to the front of the queue. These patients really do feel this card has value. They can carry it in their wallet and flash it at every health professional they see and know that it means something to those doctors and nurses. There is no doubt that they feel more enveloped - that someone is keeping tabs on what's going on, that their care is more co-ordinated. Families also feel someone else is advocating for them and supporting them."

Airedale CCG and NHS Hospital Foundation Trust was another early pioneer of the gold patient concept, having introduced GSF to primary care, care homes as well as whole hospital, building on the principle that this is first step to offering care coordination and discussion. These 'gold patients' were given a 'gold card' and access to 'Gold Line' support including being offered an advance care planning conversation about their illness. With funding from Health Foundation, the dedicated Gold Line was a 24-hour help line dedicated to people identified as being in the last year of life and their carers. Patients and carers co-designed the line with health professionals. Now, rather than using 111 they can call the Gold Line and speak to someone for reassurance and guidance. Anyone in Airedale who has been identified as being end of life, will be asked to consent to go onto the GSF register and the Gold Line. They are given a leaflet that explains precisely what that means as part of a wider

conversation. People want to feel that they are understood and their needs listened to. They don't want to have to tell people over and over their story and they want their care to be co-ordinated and joined-up." More than 1100 people are registered to the Gold Line in Airedale, while there are 1700 deaths a year. In 2016 more than half of those whose death was expected enjoyed Gold Line support. In addition, 97% of calls result in the patient remaining in their place of residence. Even more tellingly, only 14% of people registered on the Gold line died in hospital.

Morecambe Bay CCG and Hospital. Joy Wharton, Macmillan Lead Nurse for Palliative and End of Life Care, at University Hospitals of Morecambe Bay Trust says, "In my experience, most people really welcome the opportunity to have a conversation which we think they might find difficult, it can be a relief and liberating." The change of approach has had an effect on professionals and that then positively impacts on patient care. "One of the secrets to improving the experience of patients approaching the end of life and their families, is making end of life care everyone's business, putting it at the front of the mind of all staff in the hospital, not just the specialists." Stroke Consultant Dr Pradeep Kumar at Royal Lancaster Infirmary, part of UHMBT, says "I think the biggest thing has been the culture change. It's about getting patients and their families to take ownership of their care. GSF is the framework that allows us to make that happen. The best bit is making sure that patients receive the care they want, where they want it, when and how they want it and the satisfaction they and we get from that." Now, when patients are discharged from UHMBT they receive written information in a yellow or 'gold' folder. This includes a leaflet about GSF and other useful and important documents including advance care plans etc. The idea is that it reinforces the conversation staff have engaged patients in, about how, as someone with a complex health problem the hospital will be sharing their information with their GP and that their GP, with their consent, add them to a register of patients in a similar situation and that means receiving an extra level of service as well as being the subject of regular discussions. In its most recent CQC rating UHMBT received an outstanding rating for end of life care.

Nottinghamshire - Dr Julie Barker. In Mid Notts a new CCG-led care-coordination initiative launched with Electronic records or EPaCCS in 2018, to share patients' information and wishes county-wide for their GSF or gold patients. With the new initiative comes patient access to a phone line for all those Gold patients registered on EPaCCS. The call handler will receive an on-screen alert and they can pass the call through to the clinicians co-located in the call centre. Up to now, people have had to use the 111 or 999 services and these have often proved to be a major stumbling block in the way of them receiving the right care promptly. Dr Julie Barker, End of Life Care Lead at Mid Notts CCGs says: "This should make an enormous difference as people can bypass 111 and speak to people who will know about their needs and be able to alert their designated GP. "The aim of the new initiative is to prevent people falling through the net. To that end we have engaged all members of the alliance - including the hospital, Sherwood Forest, our out of hours provider, primary care, and the ambulance service, EMAS, as well as social care. We have undertaken that end of life care is everyone's business. I believe that is the secret to improving people's experience of care in the final months - empowering professionals to take ownership and be accountable." Dr Barker also believes that the simple adoption of the word 'gold' will have a positive impact. "We will start referring to people as 'gold' patients and I think that switch in terminology is really important. It will reduce the barrier to registration and provides people with a much more comfortable term. Being called gold should make them feel special and provide them with the confidence and assurance that their needs will be met."