

Airedale, Wharfedale,
Craven and Bradford
Gold Line:

Information Sharing Gold

In 2013 Airedale hospital launched its Gold Line, as a response to its local review of 'End of Life Care' and inline with the national Gold Standard. The aim is to reduce avoidable hospital admissions and support patient's choice around their preferred place of their death. In plain terms, helping to make the lives of patients approaching the end of their life (and their carers') a little easier. The service is offered during the last year of their life, giving them back some power, independence and dignity in terms of their end of life choices. Bradford and Airedale know that the majority of people's preferred place of death is often in the sanctuary of their own home and with their loved ones alongside them rather than in what can be the unfamiliar, impersonal environment of a hospital.

Airedale's local review of End of Life Care identified that they needed to develop information sharing to support their work on three strands:

1. Information sharing to identify individuals who could benefit from the Gold Line service

Bradford, Airedale and Craven use their Integrated Digital Care Record (IDCR), which holds and enables the sharing of the electronic health and care data about an individual, their condition and wishes, as the vehicle for meeting the national requirement of a local electronic end of life register, referred to as an Electronic Palliative Care Coordination system (EPaCCs). All patients that are entered on to the Bradford and Airedale IDCR can consent to share all or some of their information with other health and care providers.

2. How to talk to patients about the benefits and implications of recording and sharing information on their 'End of Life Care' choices

For professionals these difficult conversations, that need to include asking for consent to share information, are challenging because death can be a very difficult issue to talk about for all concerned. Professionals, patients and carers can be anxious, uncomfortable and sensitive when having these conversations. Whilst to some individuals the conversation can come as a shock to others it may be a welcome conversation and actually offer some relief. It is a conversation that if done well and sensitively, can transform the next part of the patient's journey.

Through these conversations health care professionals in any setting have a role in being able to identify a person in the last year of life. With the early sharing of information this can enable their GP to have the necessary conversation with the person that will see them registered on EPaCCS, secure their consent to share their information and also offer them the support of the Gold Line.



3. How to share and use information to best to co-ordinate the patient's onward care

There were many information sharing challenges to the implementation of the Gold Line which is the operational set up that uses a patients shared information on the IDCR to co-ordinate their care. Firstly building up the relationships, understanding, and trust with GPs to ensure that they put the necessary information on to the IDCR and secure the required patient consent to share their information. The second challenge was to recruit the staff with the right blend of skills, experience and personal qualities for the Gold Line. Staff need to be able to work via the telephone directly and sensitively with patients, carers; secure the confidence and trust of other professionals who are providing part of a patients treatment; and use the patient's personal health care information provided through the IDCR to monitor and coordinate their care.

A clinicians perspective...



"The opportunity for Gold Line arose from the push from within Airedale Hospital and the opportunity of using the Bradford and Airedale Integrated Digital Care Record (IDCR) that was already in place.

We knew there was a need and desire to do something differently. Patients and carers would tell us about their experience of our end of life care system, during the most emotionally and physically difficult periods of their lives. They had a number of different phone numbers to call, some for in hours, and some for evenings and weekends, they also find it tiring and upsetting to have to keep explaining their situation to all the services, all at a time when they were stressed and anxious. Some just didn't

know who to call and could end up calling 999 as they became more panicked. This would result in the Ambulance Service attending, taking the person to A&E and them being admitted to hospital for a stay of one or two weeks. This can happen when they didn't need or want to go to hospital in the first place.

People were exhausted by re-telling their story. It is like ringing an insurance company and explaining the situation to someone, who then puts you through to someone else and you have to start all over again".

Dr. Linda Wilson
Consultant in Palliative Medicine
Airedale General Hospital and Clinical Lead for the Gold Line

A Manager's viewpoint...

The Gold Line is constantly changing and improving the patient's experience. As it's not a traditional service we are able to do things differently to find ways of joining up, share information (with consent) and work collaboratively with partner agencies.

We wouldn't be able to do this without the IDCR shared electronic patient record and the governance around this. The insight and knowledge from the different parts of health care allows us to understand what is going on for patients and make better assessments and quicker decisions; even if it's as simple as increasing the dose of medicine or being able to just listen. The nurses do miss the more traditional 'hands on' approach sometimes, but they get immense satisfaction by working with patients and their carers to resolve their current issue.



Nurses on the Gold Line have commented that it's really helped to improve their assessment skills and give them a deeper understanding of how the NHS and departments work and the roles of other professionals who support the same patients.

In order to get buy in for the Gold Line I had to invite people in to see what we did and discuss how we could overcome barriers of understanding and trust in specialist areas, such as chemotherapy. Using IDCR broke down a lot of barriers, which helped to embed the ethos that the record belongs to the patient and not one department or GP.

The biggest Information sharing problem that comes with managing this type of service is when patient information and wishes aren't entered correctly or are missing. I am currently working with staff who use the system and the systems developers to find a solution to this problem.

The success of Gold Line is all down to the clinical leadership and support we received, the strategic buy in and recruiting staff that were flexible, informed and had a mix of personalities and skills. Knowing that you have supported someone in their dying wishes and supported their carer or family is really rewarding

Marie Buchan
Telemedicine Manager Airedale NHS Trust

The Gold Line is a dedicated 24/7 care and coordination service for people who are in the last year of their lives. The service shares information through the Bradford IDCR and acts as a single point of contact for the patient and their carer's and supports the delivery of care in their preferred setting and gives access to information, support and services. The key aim of this service is to provide one number to call for help and support.

The Gold Line is primarily telephone based and made up of a small team of senior nurses based at Airedale Hospital, who can access the health records of patients and offer a 24 hour 7 days a week dedicated, professional and personal service. In addition to the telephone, a small number of patients are offered an iPad and can contact the hub using bespoke video-consultation software allowing a face to face

discussion. The nurses are highly skilled, highly motivated and extremely patient centred. Having access to full health records ensures that they are able to respond quickly and accurately. They also have access to a menu of interventions:

- ▶ To arrange for a GP or district nurse to see a patient
- ▶ To admit them straight to hospital or a hospice
- ▶ To access an on call consultant.

One of the main aims of the Gold Line is to support people to stay at home when it is safe to do so and ultimately die at their preferred place of death. Airedale has achieved the lowest hospital death rate in the country with just 14% of those signed up to the Gold Line passing away in hospital.

A Nurses Opinion...

The role of a nurse working on a ward differs from that working in the Gold Line's telemedicine environment as you are using the same knowledge but relying on a different set of skills.

In standard critical care you are touching, speaking and seeing a patient and assessing all of the signs in front of you, compared to telemedicine where you are relying on listening, speaking and questioning the carer and patient to assess and identify the correct treatment. The move away from more traditional nursing methods means I am constantly using the patient as my hands and listening to what's being told to me from someone else's physical examination of a person - we sometimes do use video link as well.

This job requires me to not only use my practical knowledge, but at the same time have access to a patient's ratings and health visit notes to build up a picture whilst understanding their wishes. I think it has improved my skills as a nurse because I have been able to have sensitive and frank conversations and in some cases reach down the telephone and give support and comfort - it's pushed my skills to the limit.

As a result of this I am more confident and more able to teach a person my skills over the telephone so they become my hands, ears and eyes. What's good about the electronic record system is the reduced use of acronyms and abbreviations in order that we can quickly use the information to assess what we are being told to us by the patient or carer.

As nurses the way the Gold Line is set up means we regularly review how we work and so are able to influence clinical and best practice, and so really help improve the outcomes for our patients.

Alex Blake
Telehealth Sister with the Gold Line

The Gold Line was launched in Airedale in 2013 and scaled up to cover Bradford a year later. It is still very early days but, following the ending of the initial external funding from the Health Foundation which supported its set up, it is now directly commissioned by the local CCGs and is embedded into health's offer to patients.

The outcomes do speak for themselves. The Gold Line deals with and resolves 40% of the calls it receives which means only the remaining 60% now needs to be referred on. It has also had unexpected benefits; it can be quite scary looking after someone who is dying and things can often seem a lot worse in the middle of night, so it has become clear that the anxiety of carers and their confidence that things are 'under control' can be a major contributor to a hospital admission. The Gold Line team are there to identify the intervention needed, liaise with other professionals and so provide the support and reassurance that carers and patients need to confidently manage their situation and reduce that anxiety. Ultimately this means that hospital admissions are reduced.

A Carer's experience...



Angela wants to tell her story so she can help people better understand how information sharing has helped and improved her and her husband's life.

"Before the Gold Line we would always end up in hospital. My husband's breathing issue would require me to call 111 or 999. Depending on who I got I could be on the phone to eight people spending ten minutes repeating my story, whilst getting more and more scared. I've been married to my husband for 38 years and he gets upset when he sees me losing control. At the GP surgery we had a named doctor designated to us but we didn't actually manage to speak to him over two years of visits and calls!

Sometimes when my husband would get to A&E he would get the extra blast of oxygen he needed and would be fine, but then he would still end up being admitted to hospital for monitoring for two or three days.

It was our son who suggested that because of these trips to the hospital and the stress that we were both being put under we should think about using a hospice. We both went along and the first thing they offered us was the Gold Line. Considering that we had been going through this for a long time we didn't know why a GP wouldn't have referred us sooner.

In just three months the Gold Line has literally changed our lives. I am able to talk to a nurse when he is unwell and discuss medication options - they have helped me to be more confident in managing his condition and in taking practical steps to improve his situation. In one instance they stayed on the phone whilst a doctor came, and they have called me back to tell me if a doctor or nurse is going to be delayed. All of my husband's information is put on the record straight away, so the Gold Line nurses can discuss exactly what medicine he has and how much he can take.

Our lives are much calmer now and it's been a real help knowing that there's always someone available to reassure or support me. I just wish we had had this service earlier because it has taken the frustration and the fear out of what we have to do. One number, one call and everything is sorted - no chasing for appointments. I cannot praise the staff enough.

Angela Pettlewell

A Carer whose husband David is a registered patient with Gold Line

The Gold Lines Next Steps

Bradford Airedale and Craven currently have 1,200 patients registered through their EPaCCs, out of an estimated potential 3,500 people who are terminally ill and in the last 12 months of their life, so just under (35%). The next steps are to:

► Increase registration of individuals on the EPaCC and increase the uptake of the Gold Line. One of the areas of interest is to develop better links with Adult Social Care. It is recognised that social care professionals are a major opportunity for referrals as they see people over longer periods and may be able to highlight a significant deterioration in their condition. The challenge is to enable information sharing to happen early on in regards to those individuals who they care for and who could benefit from the Gold Line.

► Resolve the situation that currently means the sharing of a patient's health information stops once they die and explore how with improved sharing this information could support the evaluation of end of life care and identify improvements for the Gold Line service.

► Strengthen engagement with GPs, other health care professionals and the ambulance service in the area to raise awareness of the Gold Line service and ensure professionals understand the importance of and are confident in having those difficult conversations. This means people who need it will receive clear messages about the benefits of being registered on the EPaCCs and how their consent to share their information is essential to support their care.

To read more about the Gold Line go to:

www.airedale-trust.nhs.uk/yourhealth/services-and-support/gold-line/

Or

Watch the film produced by the health foundation at:

www.health.org.uk/gold-line



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