

Briefing for the Scottish COVID-19 Inquiry: Impact of the COVID-19 pandemic on charitable hospices

About this briefing

This briefing has been prepared by Hospice UK for the Scottish COVID-19 inquiry team. It gives an overview of key issues that staff working for charitable hospices have shared about their experience during the COVID-19 pandemic. It is based on conversations, focus groups and feedback gathered from staff during and after the pandemic.

Hospices in Scotland

Charitable hospices in Scotland support over 22,000 people each year, providing expert palliative and end of life care to people in their local community, and supporting families and carers throughout their illness and into bereavement. Hospices support people with any terminal or life-shortening condition, across all ages. The majority of hospice care is delivered to people at home or in the community, through home visits, virtual services, outpatient clinics or day therapy services. Inpatient units provide specialist palliative care to people within a hospice. Hospices may also provide services such as drop-in information centres, welfare advice, respite services, bereavement and counselling services and befriending initiatives.

Hospices are an integral part of the health and social care system in Scotland. They work in partnership with GPs, district nurses, care homes, hospital teams, social care and other services to support people with palliative care needs across all settings. Hospices provide education and training, specialist advice and support, and strategic leadership in palliative and end of life care locally and nationally.

There are 16 charitable hospices in Scotland. 14 provide care and support to adults and their families. Children's Hospices Across Scotland (CHAS) has two hospices that provide palliative and end of life care for babies, children and young people and respite for families, as well as its CHAS at Home service in the community, virtual hospice service and hospital based teams. Marie Curie has a community nursing service in 31 local authority areas in Scotland, in addition to its two adult hospices and other support services.

Charitable hospices are not part of the NHS. On average, just over a third of adult hospice care funding comes from statutory sources, with hospices having to fundraise the remaining two thirds themselves. Not every health board in Scotland has a charitable hospice, and the NHS and other partners provide specialist palliative care in areas where there isn't a hospice.

Key issues faced by charitable hospices during the COVID-19 pandemic

1. Rapidly changing guidance

- **Constant change:** Keeping up to date with the very high volume of national and local guidance was a big challenge for hospices. Guidance could be issued multiple times a week and changes needed to be constantly communicated to staff, patients and their

families. Going through guidance, translating what it meant into the hospice context and making sure the correct guidance was being followed took a lot of time and resource. Hospices also provided clinical leadership and advice in the development of national guidelines and local protocols, such as symptom control, access to medication and visiting, as well as participating in local and national planning, and contributing to the research community's rapid response to the pandemic.

- **Unclear where hospices 'fit':** A major concern was that for many months national guidance did not specifically mention or consider the needs or context around hospices. It was unclear whether hospices should follow guidance aimed at hospitals, community services or care homes. This all created uncertainty, anxiety and a feeling that hospices were 'on the back foot'. CHAS also felt that a lot of guidance was very adult focused. Marie Curie, who has services across the UK, experienced discord when Scottish guidance differed to guidance being followed by other Marie Curie services in England.

2. Access to advice and support

- **Variation in local support:** many hospices had strong, supportive relationships with local infection control and public health teams. These were especially helpful in supporting hospices to plan ahead and when interpreting what guidance meant for hospices. However there was variation across Scotland in terms of the support hospices were able to access. In one area public health/infection control support changed within the health board without the impact on hospices being considered, leaving them with a significant gap in expertise. Local advice given to hospices could also vary across Scotland, for example in terms of what constituted an outbreak.
- **Named contact:** hospices who had a named contact to access for advice and to respond to specific questions found this incredibly helpful. One hospice described having a named contact within Health Protection Scotland as a 'game-changer', but they did not have this until the end of 2020 and felt that if they had this from the start of the pandemic it would have made a big difference.
- **Healthcare Improvement Scotland (HIS):** The relationship between hospices and HIS (who regulate charitable hospices) was mixed. There was a general feeling that HIS was late to act and unsure of their role. Some felt that they placed an unnecessary amount of burden on hospices instead of taking a more pragmatic approach and gave advice that was sometimes confusing or conflicted with other guidance. Others found the HIS team on the ground helpful and had more of a positive relationship.
- **Scottish Government:** the relationship, advice and communication from the Scottish Government palliative care policy team was felt to be very good. The consistent messaging from Scottish Government's National Clinical Director, Jason Leitch, was positive and hospices appreciated his help when they reached out with a specific query over visiting guidance.

3. Rapid changes to service delivery

- **Rapid change:** Hospices very quickly adapted their services to continue to provide vital palliative and end of life care and bereavement support in their communities. Staff stepped up, changed roles and worked very flexibly, in a challenging environment.
- **Increased care in the community:** With more people dying at home and in care homes during the pandemic, hospices expanded the support they provided in the community through community hubs, hospice@home and rapid response services, and offered more support to care homes and community teams. This meant quickly redeploying staff and volunteers to respond to the additional need and increased complexity of care in the community. Hospices generally had fewer patients referred into their inpatient units as more people were being cared for at home.
- **More virtual support:** Hospices quickly shifted to using virtual technology where face to face support was not possible, providing virtual consultations, online wellbeing hubs and counselling and bereavement support via phone and video consultation. Virtual services allowed hospices to continue to support patients and families when a lot of routine services had to be cancelled, such as day therapies and respite services. However it was a big learning curve for families and staff to use technology in this way, technology could be unreliable and some hospices needed to invest in IT infrastructure to support this shift.
- **Strengthened partnership working:** Hospices worked closely with care homes, GPs, community services and acute care, and increased the support and training they provided to staff across different settings. There were many positive examples of innovative partnership working. Some hospices said they made additional offers of support that were not taken up, for example, more support to care homes and offers of beds to the NHS.
- **Increased bereavement support:** Hospices expanded and adapted their bereavement services as the need for bereavement support increased throughout the pandemic, using their strong community links to recruit and train additional volunteers.
- **Dedicated covid unit:** Kilbryde Hospice in East Kilbride became a dedicated covid unit between March – May 2020, at the request of NHS Lanarkshire, to care for people with covid at the end of life. The hospice was taken under NHS Lanarkshire during this time and stopped being registered with Healthcare Improvement Scotland. The number of patients seen was small however it was very challenging working environment for staff. Patients died very quickly after being admitted and it was hard for staff and families not having the time to build up a relationship. The hospice also provided a hub for NHS staff and developed a complementary wellbeing service for the intensive care staff at Hairmyres Hospital.

4. Supply and use of Personal Protective Equipment (PPE)

- **Shortage of PPE:** A survey of UK hospice and palliative care services (including NHS services), found that approximately a third of services in Scotland experienced shortages

of PPE during the pandemic¹. Third sector services, such as hospices, were particularly impacted because they are often considered to be outside of NHS supply chains. Some hospices found it incredibly challenging to access PPE, especially at the start of the pandemic. One hospice talked about having to ration which staff members could see a patient because they were so short of face masks. Even for those that were in local supply chains, accessing PPE could be difficult because the quantities needed were suddenly so much greater. Once proper procurement chains were established access became easier. Hospices also received generous donations of masks, hand sanitiser and other PPE from members of the public, businesses and dentists, though some supplies were not suitable for hospices to use.

- **Variation across Scotland:** The supply of PPE to hospices varied across Scotland, with those in some areas, for example Lothian, finding it very challenging. Some hospices needed to borrow from others or redistribute supplies received in one part of the country to another. There was variation in whether hospices were part of NHS supply chains, how easy it was for them to be included and how PPE was paid for. There were also questions raised by some local Health and Social Care Partnerships about whether hospices should be included because they were not NHS services. One hospice reported that they were not initially recognised as an 'essential service' by their Health Board, but once they were it became much easier for them to access PPE and other support from the health board.
- **Fitting masks:** Fittings of FFP3 masks was also challenging for some hospices. One hospice talked about eventually getting FFP3 masks but not having anyone who could fit them. They then received training but did not have any kits to fit the masks. It felt like 'one thing after another' with each stage of the process being slow and hospices not being considered. It took almost a year before they had a clear supply of FFP3 masks.

5. Vaccinations and testing

- **Variation across Scotland:** There was variation across Scotland in terms of how easy it was for hospice staff to be included in covid testing and vaccination programmes for healthcare staff. Some hospice staff received their vaccines and boosters at the same time as NHS hospital staff but others experienced a delay of several weeks or months. In areas where hospices were included in their local health board's system for booking vaccines and accessing testing, it was quicker and easier.
- **Lack of mechanism to include hospices:** While Scottish Government guidance was clear that hospice staff are frontline health and care staff in relation to testing and vaccinations, in some areas there was no local mechanism in place for hospice staff to access this. For example if they did not have NHS email address to book vaccine slots. Hospices had to seek out information and were reliant on local contacts, networks and exchanging information with other hospices instead of being told clear and consistent information. Some found it quite chaotic at the start of the vaccination programme, when they would receive phone calls about vaccine slots available the next day and would

¹ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2021/better-end-of-life-report-briefing.pdf>

need to prioritise and phone around their staff to fill the slots. Once hospices were in the local system for booking vaccines they received them at the same time as NHS staff.

6. Impact on hospice fundraising

- **Emergency funding:** The restrictions of the pandemic had a devastating impact on hospices' ability to fundraise at a time when hospice services were needed more than ever. Large parts of hospices' income streams essentially stopped overnight. Hospice UK campaigned for emergency funding to support hospices during the pandemic. The UK Government agreed emergency financial support for hospices in England. Following this, Scottish Government agreed to pass on all consequential funding to hospices in Scotland. In total, a £27 million emergency funding package was allocated to Scottish hospices from Scottish Government during the course of the pandemic. This was strongly welcomed by the sector and provided short-term stability, allowing hospices to continue to provide vital care to people in their communities.

7. Visiting restrictions

- **Restrictions on visiting:** Restricting the number of visitors within hospices had a huge impact on patients, families and staff. It is the area that staff talk about as causing the most distress, and this is explored in more detail in the sections on staff, and patients and families, below. While the majority of hospices continued to allow visiting throughout the pandemic, a small number did stop all visiting at the beginning of the pandemic when there was still a lot of uncertainty and anxiety around what was safe to do.
- **Different interpretations of visiting guidance:** though visiting at the end of life was permitted there were different ways to interpret the guidance, for example whether 'end of life' meant the active stage of dying in the last few days or whether it should be interpreted more widely. Hospices took different approaches around this and in terms of the numbers of visitors they allowed, the length of time they could visit and whether they were 'named' visitors. Because of the lack of clarity, hospices approached National Clinical Director, Jason Leitch, directly and found his advice about taking a flexible and compassionate approach to visiting to be very helpful.
- **Hospice buildings:** visiting also depended on the physical structure of hospice buildings. Some hospices were fortunate to have direct access from outside to single patient rooms, which allowed for more flexibility. Some built shelters or put up gazebos to allow families to sit outside while their loved one was in their room. Multiple occupancy rooms were more challenging and where possible, hospices shifted to all single rooms to help keep patients and families separate.

8. Impact on hospice staff

- **Changes to working conditions:** With the rapid change to how services were delivered, the working conditions for staff changed very quickly too. At the beginning of the pandemic the sheer level of uncertainty and having to constantly get used to different sets of expectations was very unsettling. Some frontline staff felt like they were working 'with their hands tied behind their backs' and not being able to make their own decisions

or have agency in their roles. Staff in leadership roles also found it challenging to suddenly switch from a collaborative and consultative leadership approach to a crisis, top-down leadership mode. Staff felt more isolated and found it harder to keep relationships strong and have the peer support they were used to when they didn't see colleagues everyday.

- **Ethos of hospice care:** Hospice care is about providing holistic care to patients, their families and loved ones. Staff found it hard not being able to deliver care in the way they normally take pride in as palliative care professionals. The conversations that staff had with patients and family members about visiting were particularly distressing and went against everything that staff would normally try and accommodate. Staff felt like they were adding to families' stress when normally they can ease it and that they were 'gatekeepers instead of enablers'. Good communication is a key skill in palliative care and it was very challenging for frontline staff to communicate and build relationships with patients, families and colleagues when wearing PPE and social distancing. Trying to maintain the ethos of hospice care while using virtual technology or not being able to touch or comfort people in the same way was hard.
- **Weight of responsibility:** Hospice staff were juggling the responsibility they felt towards their patients and their families, with the responsibility for their colleagues, alongside managing their own family's needs at home. It was hard for staff to provide support and manage people's distress at work when they were also managing this personally. One community team leader talked about 'haunting memories' of having to ask team members to visit people in their own homes at the start of the pandemic when the risks of COVID-19 were unknown and before people were vaccinated. Staff felt additionally responsible when there was little involvement from other health and care professionals, and they were some of the only people still seeing patients. Some staff also felt fear and anxiety around whether they doing enough to protect their patients from catching COVID-19 because of the devastating impact that would have on their vulnerable patients. Staff felt emotionally and physically exhausted by what they were experiencing.
- **Keeping staff safe:** Safe practice for staff was a big issue and it took several months before there was clear guidance around managing staff to staff transmission. Hospices had staff who were vulnerable and needed shielding too. Before there was clear guidance or shielding letters it was hard for hospices to know who needed to stay at home to keep them safe.
- **Staffing levels:** Maintaining staffing levels was challenging especially when staff were off sick or needed to isolate when they were identified as a contact. This put additional pressure on remaining staff. There was no statutory funding for backfill or sickness absence and resources were challenging. Recruitment and retention was an issue for some hospices.
- **Impact of furlough:** The introduction of furlough was complex. Hospices needed to put some people on furlough to save money but it also created discord within teams between staff who were still at work and those that were furloughed. There was also an added burden on staff who had to take on additional roles and workload because other colleagues were furloughed. Some staff who were furloughed felt guilty, while others felt

devalued. Some hospices regretted furloughing certain roles, such as occupational therapists and physiotherapists, and realised how important their skills were.

- **Support to staff:** Hospices supported their own staff and staff in other health and social care settings to cope with the challenges of the pandemic and traumatic experiences of death. Many wider health and care staff were exposed to death, dying and bereavement at levels they will have never experienced before and this will have had a lasting impact. One hospice expanded the capacity of their Family Support Team and undertook additional training on working with trauma, to support to other health and care staff working locally who had traumatic experiences of deaths during the pandemic.

9. Impact on patients and families

- Patients and families' experiences during the pandemic were very personal and varied widely. The points below reflect some of the themes shared by hospice and palliative care staff who supported patients and families in hospices and in the community during the pandemic.
- **Visiting restrictions:** The restrictions to visiting in hospices were very distressing for families and patients, especially when some hospices had a period of no visitors. There were cases of hospice patients dying with no family present; of dying patients who had three children who were only able to see two of them before they died; patients not being able to see their young children for long periods; and family members working in caring roles elsewhere who felt unable to visit loved ones because of the risks of passing on COVID-19. Families sometimes challenged hospice staff around the visiting restrictions and there were a small number of complaints made by family members. The distress felt by families was compounded after people died by the restrictions around funerals.
- **Isolation and the impact of shielding:** Patients in the hospice felt very isolated because of the restrictions around visiting, people being in single rooms and the steps that hospices had to take to maintain social distancing. People who were being supported by hospices in their own homes also felt very isolated. These people were very often shielding and unable to see friends and families who they relied on for emotional and practical support. Families felt guilty that they were not able to visit or support loved ones in the way they wanted. The isolation that people felt took a physical and mental toll and there was a lot of emotional exhaustion from patients and carers. This was sometimes made worse by financial concerns because of people being on furlough or a reduced income. Some patients also felt angst at spending their 'time left' in lockdown and not being able to do the things which mattered most to them, such as spending times with loved ones or travelling. As time went on patients and families became more and more isolated and it became harder for staff to provide support and manage people's distress.
- **Anxiety:** The level of uncertainty was hard for patients and families. Some people were anxious about carers coming into their homes and the risks this would bring. There was also initial uncertainty about whether this was allowed until specific guidance was issued around delivering care to people in their own homes. Even when restrictions eased,

people still felt anxious about whether they should see friends and family more. Family members who went back to work also felt anxiety about bringing the virus home.

- **Lack of support:** Many wider community services stopped and this sudden withdrawal of support, alongside people not being able to access their normal coping strategies, was very challenging for patients and families. In some cases people found it difficult to access support for shopping and medications. Some families felt abandoned by health and care professionals, while others did not want carers coming in to their homes. Some hospices reported that referrals from GPs went down and they were worried that patients were not seeking or accessing the support they needed. They were also concerned that with people being seen less frequently and more remotely changes would not be picked up or acted upon. Carers also felt unsupported and were unable to access services such as respite.
- **Communication:** It was hard for patients and families to not be able to speak with or get the information they wanted from wider health and care professionals. The lack of communication made patients and families feel disconnected and added to the sense of isolation. Some families felt a lot of anger that was sometimes directed at hospice staff because they were the only professionals they were seeing. Some hospices saw complaints from families, not necessarily about the hospice itself, but because of the lack of communication and co-ordination across community services. Some staff raised concerns that other care professionals struggled with conversations around death, dying and bereavement, demonstrated by inappropriate use of Do Not Attempt Resuscitate Orders, resulting in confusion and distress amongst families and staff.

10. Impact on children, young people and their families

- **Fear and anxiety:** Many children and young people with life-shortening conditions have compromised immune systems. Feedback that CHAS gathered from the families they support emphasised the fear families felt for their children during the pandemic. Many families locked down much earlier than 23 March 2020. Lots of families took shielding very seriously and did not leave the house or let other people in. They did not want to come into the hospice or have hospice staff or other carers come into their homes. Only families who were really struggling came into the hospice.
- **Lack of support:** Other families really wanted more support and were frustrated by the lack of availability from wider services. Families were incredibly grateful for the support that CHAS continued to provide. Entertaining children and young people was a constant challenge. It could be hard for families to access food supplies and meet special dietary requirements. Some families did not receive a shielding letter, even though their children had hugely complex medical issues because their child did not have a clear diagnosis needed to be on the shielding list. This caused frustration and fear with parents being too concerned to go out but unable to access priority deliveries.
- **Easing of restrictions:** There were lots of concerns from families around the easing of lockdown measures and the rising rate of infections. A significant number of families with children with life-shortening conditions did not send their child or their siblings back to

school when they re-opened. Parents were concerned of the potentially huge impact that contracting COVID-19 could have on their child. At the same time they were concerned about their child's education and socialisation. When schools reopened, parents were worried that there were no additional measures in place for previously shielded children and they did not know how to keep their child safe if their siblings were coming into contact with numerous people during the school day.

- **Lack of tailored information:** Families felt that there wasn't enough tailored information for people in high risk groups at the beginning of the pandemic and when restrictions were easing. Guidance about returning to school was a uniform policy across all children, with no obvious considerations given to the unique circumstances of children with life-shortening conditions. Parents felt that the Scottish Government should have provided more national guidance instead of parents having to interact with local authorities. In addition, local authorities and schools were unable to give bespoke advice because guidance had not been developed at a national level. Parents felt that guidance requiring individual risk assessments and plans appropriate to their child's condition and needs would have been helpful.

11. Impact in the community

- **More people dying at home:** During the pandemic people continued to die of terminal conditions, such as cancer, heart failure, dementia and many other conditions. But the pandemic saw a big shift in where those people were being cared for and were dying, with deaths at home increasing by over a third during the pandemic. The shift in more people being cared for and dying at home was already happening prior to the pandemic, but during the pandemic this trend rapidly accelerated. Marie Curie saw nearly a 15% increase in demand for their community nursing services across Scotland and hospices typically saw more patients in the community and fewer patients in their inpatient units. The shift to more deaths at home could be for a number of reasons. More family members were furloughed or at home and were able to give the care they wanted to loved ones. At the start of the pandemic there was a very rapid push to discharge people from hospitals into the community. People were also scared to go into hospitals or inpatient units and wanted to be at home where they could see their family. It is important to try and fully understand why more people were able to die at home, what support was available to them and their families, and what their experience was like.
- **Pressure on community services:** The shift to more people being cared for at home put huge pressure on families and carers, and on community services. In some areas very few professionals were visiting people at home. Several hospices raised concerns that it was hard for patients to access GPs and that GPs were not visiting people at home. This added to the pressure felt by other teams, such as hospice and palliative care staff and district nurses, who continued to visit patients at home. The complexity of care needed was higher, visits took longer and going into a patient's home could also be more challenging. Staff sometimes had to say to families that they couldn't come into a room because there were too many people in there. It could be hard to set down boundaries but staff also wanted to do it to feel safe.

- **Access to social care:** Feedback from palliative care social workers emphasised that access to social care and care packages was very difficult for palliative patients being cared for at home. They gave examples of patients being discharged from hospital without a care package in place with the expectation that families would take on the care until the care package started. The drive to get people home quickly from hospital meant people with complex care needs were being discharged with little anticipatory planning and a lack of social care support. Families would take relatives home without an understanding of what that meant and without adequate support, equipment or the home environment set up appropriately. This put a huge stress on families and carers, leading to patient and family distress and sometimes crisis readmissions.
- **Increased complexity of care:** Hospice and palliative care staff were seeing patients with much more complex care needs and managing more complex situations at home than before the pandemic. There was also an increase in the complexity of needs of carers and families as well as patients.

12. Long-term impact of the pandemic

- **Late diagnosis:** Many people were unable, or felt anxious, about accessing health services during the pandemic, particularly in the first few months. As a result, hospices have seen people being diagnosed and given a terminal diagnosis much later in their disease trajectory. People have also been accessing hospice and palliative care services later than normal when their needs are much more complex. Hospices have seen people dying more quickly after they have been referred. This is hard for families who do not have time to prepare for the person's death or build a relationship with staff. It is possible that some patients could have had better outcomes if they had been able to access services earlier on. Some hospices have also been seeing more younger adults in their 30s and 40s with terminal conditions. Anecdotally, CHAS felt that the children and young people they supported were less ill and there were fewer deaths than expected during the pandemic because children were not exposed to respiratory diseases and had limited mixing.
- **Bereavement:** Hospices have talked about a 'tsunami of grief' in communities being a lasting impact of the pandemic. There is lots of complex bereavement, emotional distress and poor mental health in communities, especially where families were not able to be with their loved one at the end of life or where they feel they may have missed out on care. Wider health and care staff are also dealing with the long term impact of being exposed to much higher levels of death and dying, sometimes in very traumatic circumstances.
- **Different public expectations:** Some hospice staff talked about people having different expectations of health and care services now. People's expectations are much higher but their tolerance of what they can cope with is lower. The lack of communication with health and care professionals during the pandemic and the distress this caused is still impacting some families. Some staff felt there has been a loss of trust in healthcare professionals.
- **Impact on staff:** There has been a long-term impact on hospice and palliative care staff. Some are only now seeing the full impact on teams because people have not had a

chance to process and recharge. Staff still talk about and feel affected by their experience during the pandemic. Some hospices are seeing higher staff sickness and lower resilience. Emerging from covid, staff have had to re-build teams. Some hospices did not have staff available to fully re-open services when restrictions were lifted. The healthcare environment they work in has changed and staff had to get used to working in a different way. It took a while for staff and services to reach a 'new normal'. Some hospice staff have struggled to adapt and have moved on from posts.

13. Positive impact of the pandemic

- **Removal of barriers:** One positive aspect of the pandemic that hospices raised was the breakdown of usual barriers and bureaucracy both internally and when working with external partners. Staff realised how quickly service change could take place when people were focused on working together and responding to a crisis.
- **Partnership working:** The pandemic has been a catalyst for developing closer partnership working and collaboration between hospices and other services. There were innovative examples of multi-agency and multi-disciplinary working. These closer relationships and improved communication have remained and the long-term links with partners has been positive.
- **New possibilities:** The pandemic resulted in a lot of worthwhile learning and opening up of opportunities. Some hospices had previously considered changes to services, such as introducing virtual support, and the pandemic was the catalyst to make this happen. There has been a lot of learning from introducing these challenges and a broadening of views in terms of what hospices can do, for example supporting people at home with much more complex needs. Hospices have kept some service changes introduced during the pandemic, for example adopting a hybrid approach to face-to-face and virtual services that has allowed hospices to extend their reach and allow people to access services without needing to travel into the hospice. Others have embedded community models that were piloted during the pandemic.

About Hospice UK

Hospice UK is the national charity for hospice and end of life care. We work to ensure everyone affected by death, dying and bereavement gets the care and support they need, when they need it. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life. Our membership includes all charitable hospices in Scotland.

Hospice UK would be happy to provide further information about any of the issues raised in this briefing. For further information please contact:

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Definitions

Hospice care: Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different.

Palliative care: The World Health Organisation defines palliative care as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care is explicitly recognised under the human right to health.