

Health and Social Care Committee

Oral evidence: Hospice Funding, HC 709

Tuesday 23 April 2024

Ordered by the House of Commons to be published on 23 April 2024.

Watch the meeting

Members present: Steve Brine (Chair); Chris Green; Mrs Paulette Hamilton; Rachael Maskell; James Morris.

Questions 1 - 43

Witnesses

[I](#): James Cooper; Head of External Affairs, Together for Short Lives; Dr Syed Qamar Abbas, Medical Director, St Clare's Hospice; Ruth Driscoll, Head of Policy and Public Affairs in England, Marie Curie; and Toby Porter, Chief Executive Officer, Hospice UK.

Written evidence from witnesses:

- [Add names of witnesses and hyperlink to submissions]

Examination of witnesses

Witnesses: James Cooper, Dr Abbas, Ruth Driscoll and Toby Porter.

Q1 Chair: Good morning. This is the Health and Social Care Select Committee. It is Tuesday 23 April and we are live in the Palace of Westminster in Committee Room 16. We have a cross-party Committee of MPs for what we describe as one of our topical sessions.

Last night, in the main Chamber of the House of Commons, there was a debate on hospices. It was a Backbench Business Committee debate, which we took full advantage of in the gap between the ping and the pong of the Rwanda policy. There was a very good debate across the House about all aspects of hospices, and a number of us contributed to it. It is the perfect ramp, if you like, to today's topical session.

We are looking to explore the balance between hospices' statutory funding and other funding streams, and the challenges that they face at the moment around costs and inflation, and liaising with the wider NHS and the new ICBs—I say "new" because they are still relatively new. Of course, there is the whole impact of the hospice system on patient care. We are going to have a go at that over the next hour and a half.

I will introduce our guests. James Cooper is the head of external affairs at Together for Short Lives—nice to see you. Ruth Driscoll is the head of policy and public affairs in England for Marie Curie. Toby Porter is the chief executive officer of Hospice UK, and Dr Qamar Abbas is medical director at St Clare's Hospice. Thank you very much for joining us.

I will bring in my colleagues, but I will kick off by asking you about the new statutory duty on ICBs to provide palliative care services—not necessarily specifically hospice services but palliative services. We can unpack that, of course. Mr Porter, how do you think it is going for ICBs? How would you mark their card thus far?

Toby Porter: Not great, to be honest, in the two financial years since the legislation was passed. It has been two years when hospices have seen their financial situation become much more precarious. We are very positive about the legislation and we understand that ICBs face extremely difficult jobs. I have met many ICB CEOs and people responsible for palliative care. I know that they are very committed but, in the end, we have to go by the evidence of what we see.

What I see is an absence of strategy in funding allocations. What the Minister was saying yesterday at the end of your debate was absolutely right. There should not be a God-given right for hospices to get funding. There needs to be a strategic look at palliative care services and funding decisions that have the greatest impact on an overall service to a given population. We just don't see the evidence for that. What we see is salami-slicing and totally inadequate uplifts. People are getting similar grants to those they got five or 10 years ago, so there is no strategic rationale at the moment, and we are very worried. That is why so many



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member hospices have written to their MPs and why Peter Gibson, as APPG chair, called the debate in Parliament. This is not a drill; this is a very difficult current situation, and hospice services are being cut back.

Q2 **Chair:** Am I right in saying that you provide the secretariat to the all-party group?

Toby Porter: Yes, we do.

Q3 **Chair:** You have just produced a report as an all-party group. With regard to the ICBs' role in that, were there any particular references that you would like to draw our attention to?

Toby Porter: At the moment, we would say that the key recommendation in that report is that we need a new model for hospice funding. We understand the devolved distribution of healthcare resourcing in England but, going by the evidence, it is not working for the hospice sector or for palliative care in general. I thought there was a very good recent example from Wales, where the Welsh Government announced, the week before last, a special £4 million one-off payment to Marie Curie and the independent hospices in Wales, recognising that they needed additional financial support to help them match Agenda for Change pay awards for the last couple of years.

At the same time as that immediate support was confirmed, the Welsh Government also said that they recognise that we need a more strategic approach to try to find ways around the specific problems that charitable hospices seem to be facing. I would say that the key recommendation in England would be for a similar approach.

Q4 **Chair:** Thank you. Ruth, is it early days for ICBs or worrying signs? Are they learning fast, or do they just not have the expertise in the room, and you do not see any trajectory to them having that?

Ruth Driscoll: That is a really good question. We think that palliative and end of life care is not being recognised as a strategic priority by integrated care boards, and we base that analysis on two pieces of evidence.

First of all, we analysed the integrated care strategies and the joint forward plans that were produced in the first year of their operation. We found a very patchy picture. Some of them mentioned palliative and end of life care; others did not. Sometimes it was given a brief mention in the strategy but not followed through in the plans. It is not being recognised at that strategic level as a national issue, yet we know that it is because of our ageing population, with more people living for longer with multiple and complex conditions that will need palliative and end of life care.

The second piece of evidence was a survey that we did in the first year of integrated care systems being on a statutory footing. It was the first year after they had the new legal duty to commission palliative care. We commissioned KPMG as part of a pro bono partnership that we had with



them as a charity to do a survey of the integrated care boards in England. That gave a bleak picture of the extent to which they prioritise funding for these services: 50% of the ICBs responding to our survey told us that they have not made, or do not plan to make, significant capital investment in palliative and end of life care. Over 40% of the responding ICBs in the survey told us that current investment levels in palliative and end of life care were not sufficient to meet the needs of their local populations, or they did not know if it was sufficient.

That was a self-report from ICBs themselves about the extent to which they were able to make investments in the services, one year on from being given a legal duty to commission the services. This story is reflected in our own finances as a charity. That is the perspective from integrated care systems. We share Toby's analysis. A lot more work is needed to make it a strategic priority and to get the services funded.

Q5 Chair: Dr Abbas, you are on the frontline. You are based in Harlow at the St Clare Hospice, where you are the medical director. How does it feel in the ICB landscape that you are now almost entirely reliant on in terms of the level of your funding stream?

Dr Abbas: Some of it has already been answered very eloquently by Toby and Ruth. On the ground, perhaps I can take you back a few years to when we were integrated a lot more with the CCGs, when they were in place, and we created relationships with them. You are asking about the grants. We are in west Essex. Historically, we worked with Essex, but very rightly, when the integration got a bit bigger, rather than working with Essex we have gone towards Hertfordshire because we get on with colleagues there. We did not have the same relationship as such; people were changed a lot and a lot of time and energy was consumed in redeveloping those strategic relationships.

In the last five or six years—it started even before covid—the expectation from hospices has been higher and different. For example, in end of life care we have, rightly, started talking about frailty, loneliness and non-cancerous diseases. Obviously, that requires a bit more strategic thought and funding. It is not anybody's fault, but the way the structure was changed and the expectation of increasing services—but without much money, investment or training—was very hard to cope with.

For example, in the last year or so there has been a shift again, to Compassionate Neighbours and a compassionate community project, but that is not a healthcare-based model. It is more of a social care model. There are discussions to have with the ICB. When you talk about the small nitty-gritty and the operational things, the operation feeds into the strategy. The operational things have not been looked at on their own—for example, pharmaceutical and out of hours services. In our area we do not have out of hours district nursing to look after patients at home, which means that more pressure is put on the hospice at-home team. You have to invest more without any uplift. Strategic thought did not go into those operations.



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Q6 **Chair:** Thank you. Finally in this opening sequence, James Cooper from Together for Short Lives, you obviously provide support for children with life-threatening and limiting conditions. Talk to us about the children's hospice grant and the lack of long-term visibility on that, and the challenges that that provides. Talk to us about how you feel the ICB landscape that we are now talking about copes, or doesn't, with your sector.

James Cooper: The children's hospice grant has been provided directly by central Government and, latterly, by NHS England since 2006-07. It is now worth £25 million per year and it represents about 15% of the charitable expenditure that children's hospices in England incur every year. It is really important amid a patchy and variable landscape of ICB and local authority funding. ICB funding represents around 13% of children's hospice charitable expenditure, but it is extremely variable.

Together for Short Lives undertook some freedom of information requests of ICBs last year. From those we found that there was a huge range in the extent to which ICBs were funding children's hospices. In the amount of money going in per child with a life-limiting or life-threatening condition, the variation was over £400, from the lowest to the highest ICB. The lowest was £28 per child and the highest was over £500. If it was left to ICBs at the moment, that funding would not be sustainable. The grant is a crucial area of funding. NHS England has committed to £25 million again in 2024-25, which is really positive. NHS England wrote to ICBs a couple of weeks ago to confirm how much children's hospices should be receiving. ICBs have until tomorrow to write back to NHS England to confirm that they will distribute that money.

We still have some questions about exactly when the money is going to reach children's hospices and what the consequences will be if ICBs do not submit the returns. Certainly, based on the freedom of information requests that we have received, we are concerned about ICBs' understanding of the needs of children and young people with life-limiting and life-threatening conditions. Six ICBs could not tell us how much money they were putting into their local children's hospices, and 31% could not identify the number of children with life-limiting conditions in their particular area, so we are sceptical about devolving the grant to ICBs, but we are keen to work with NHS England to make sure that the process works.

We are concerned about what might happen beyond 2024-25. There is no commitment from the Government to maintain the grant. It is crucial. Children's hospices have told us that if that grant was removed, 38% of them would reduce the end of life care that they provide; 79% of them said that they would reduce short breaks for respite and 66% of them say they would reduce hospice at-home services. It is a really crucial picture.

Q7 **Chair:** Did you say it would stop their services altogether?

James Cooper: No, they would reduce them.



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Q8 Chair: You will be aware of Naomi House and Jack's Place, in my constituency of Winchester. Obviously, I know them pretty well. They would say to me that the uncertainty about the grant for this year is quite something, but we are already into the year 2024-25, and they have until tomorrow to write back. Presumably, it will then take some time for that to iron out.

I know that you talk to Mark Smith at Naomi House, and I am sure you talk to children's hospices all the time. Give us a sense on the ground of the practical challenges of staff planning, project builds and kit purchase that the lack of certainty and long-term visibility gives them.

James Cooper: Absolutely. It is hindering children's hospices' ability to invest in the future. They are relying on their reserves to sustain important services. Their costs are increasing. Between 2022 and 2023, charitable expenditure increased by 13%. At the same time, ICB funding reduced by about a quarter. Those costs are being driven by the cost of recruiting and retaining staff. There is a staff shortage and a workforce crisis in children's palliative care. We see vacancy rates of around 14% among healthcare professionals in children's hospices, which is higher than the average NHS rate, so it is a real struggle. The impact of the energy crisis has been profound for children's hospices. They run complex equipment, such as ventilators, suction machines and monitors, as well as keeping the heating and the lights on. It is having an impact.

Q9 Chair: Finally, sticking with this particular hospice, but it is relevant across the sector because these issues are the same everywhere, Naomi House is a children's hospice, and it now has Jack's Place attached to it. Of course, a lot of young children, sadly, would not have made it to be teenagers, but now, through advances, they are. That creates new challenges, and that is why Jack's Place was built.

How do you think ICBs cope? We have always had a system, whether you call it CCGs, primary care trusts or ICBs, and they have always had challenges with transition between childhood and adulthood. We now have childhood, teenagehood to adulthood. How do you think that is working, given that my hospice would tell me that they have to work with six different ICBs because children's hospices have a wider catchment? How do you think they are coping with that changed landscape?

James Cooper: It is really challenging. As you said, the number of young people living with life-limiting and life-threatening conditions is growing. That is a wonderful thing, but it poses challenges to the health and care system. The numbers are still small. There are 99,000 children and young people with life-limiting and life-threatening conditions across the UK. That number has trebled in the past 20 years. The numbers at ICB level are really small, so it is very difficult for ICBs to create economies of scale.

We think that ICBs need to work together on a regional basis because that is often the geographical footprint on which these services are based, either in hospitals or hospices. It is important that ICBs take



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person-centred approaches to make sure that they are putting in place the service specifications that are set out for them. NHS England have detailed service specifications that we have worked with them to produce. There is adequate statutory guidance. We have ambitions for palliative and end of life care. It is clear what they should do, but I believe that we need more accountability from the centre to make sure that ICBs are doing that, as well as giving them support to do so.

Chair: That is really helpful.

Q10 Chris Green: Ms Driscoll, the integrated care boards and the integrated care system are supposed to do two principal things. One is to bring health and care closer to the people so that you can reflect the community within the catchment area. Also, any money saved is retained within the system and can therefore be reinvested. There is a huge incentive to have strategic thinking, to save money and to reinvest in care. I have not yet had the sense from the panel that that is quite working. Do they need a little bit more time?

Ruth Driscoll: In some parts of the country there is brilliant work going on in partnership with integrated care boards. A lot of the conversation around hospice funding is negative, for really good reasons, but I wonder if I can switch it for a moment to all the brilliant stuff that hospices can do, working in partnership with the NHS. There are some amazing examples of us not just working in partnership to improve care for people with a terminal illness and their families, but of hospices managing to reduce pressures on the health and care system, which is a massive challenge for integrated care boards in England right now.

We completely understand that challenge, and we can bring so much to trying to reduce it. A great example is that there are currently more than 750,000 out of hours A&E visits by people at the end of life in the UK every year. They are coming into A&E. They are calling an ambulance and are being admitted, using hospital bed days because they struggle to access the care and support that they need when they are dying at home. They might be in their own home or in a care home. End of life care is consistently the most specified reason for urgent referrals to community response services. Those are the services that go out at speed to people who are in crisis. After catheter problems, it is the most specified reason for a referral. There were 74,420 such referrals in November last year alone, for example, just to illustrate the scale of that challenge.

During covid the Government gave quite generous emergency grant funding to hospices. They used that to introduce some innovative and impactful models of joint working in an integrated way in community settings with other parts of the health and care system. A lot of the funding for those approaches is now falling away in the context of the massive challenge around hospice funding. However, there are still some brilliant examples. I want to share one of them with you today. In Merseyside, Marie Curie is working with an independent hospice charity and with the NHS to run a 24/7 single point of access hub. It is called the



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Impact Hub and gives access to all the different services that someone at the end of life in Merseyside might need. It gets access to those services quickly, so it is really improving the quality of care that patients and their loved ones receive in the community at the end of life. It has been extended so that it does not just cover the wealthy parts of Liverpool but the poorest parts of the city.

In its first year of operation, that new model achieved a 13% reduction in emergency admissions of people in the last 90 days of their life. It brought down deaths taking place in a hospital setting. It allowed more people to die at home, which is typically where they want to be at the end of their life. There was a 13.6% reduction in the number of deaths in hospital of people in their last year of life. It has also managed to increase the number of people who are registered for palliative care on the supportive care register. That is the register of people who need palliative care in the community. By working in partnership with the NHS, independent hospices and big hospices like Marie Curie can do amazing things to bring down the pressures on the wider health and care system, but we can only do that if we have the funding to do it well.

There are other examples. I have just named one. We are running a brilliant urgent community response service in Durham, which works with district nurses to plug the gaps in their coverage of care for people who are dying at home. Another example would be specialist palliative care in-reach into A&E departments. With Bradford Royal Infirmary, we are putting palliative care expertise into A&E so that people can be diverted out of A&E and be supported through hospice care at home or through virtual wards. We are turning that round the other way to prevent them from coming into A&E in the first place. If we can get the funding—not just big charities like ours but the smaller, independent hospices—we can do amazing things to reduce those system pressures.

Q11 Chris Green: Is that in Walton in Liverpool?

Ruth Driscoll: It covers the whole of Merseyside, yes.

Q12 Chris Green: When we hear that the hospices can be very effective and value for money, do you have a concern that ICBs are clearly not adopting those services and are not reaching out as they could or should be doing? Does there seem to be a bit of a divide between ICB/NHS thinking and an external organisation? Part of the way I see that health connection is that the hospitals should be getting some of the people out into care homes and saving a huge amount of money in that way to reinvest. It seems to be a little bit like the hospices as well. The NHS and the ICBs are not using or engaging with hospices in the way they could and should to provide better care and more innovative care to save money. In certain instances that relationship is there, but even when you have good best practice the neighbouring areas are not perhaps looking at it and adopting it.



Ruth Driscoll: Yes, that is right; there is definitely a challenge around sharing best practice. One of the things that we are doing at Marie Curie is running a seminar series, where we showcase interesting models of innovative practice and joint working with the NHS to integrated care boards so that they can know about the brilliant stuff that hospice charities are doing. We are sharing not just our own practice but the practices of other hospice charities as well, but there is a really big challenge, and it is important to state it super clearly. There are massive gaps in access to these services at local level. There are massive inequalities and inequities in access to palliative and end of life care across the country. The current model of hospice funding is part of the story of why those exist.

The current funding model does not enable universal access to healthcare services in the way that NHS funding should, and does, for other aspects of healthcare. It would be an outrage if maternity services, for example, were funded in this way, where there was an expectation that charitable fundraising would cover two thirds of the cost in many cases. Just to give you a sense of Marie Curie's services, our hospice services were only 36% funded by statutory income. Our community nursing services are slightly better funded at 49%. The rest of the money has to be found through voluntary income.

In practice, that means that our income is not meeting the costs of running these essential services. We had a deficit of nearly £9 million as we left the last financial year. We will have to continue that deficit in the coming financial year. Our service costs rose by £15 million in the last financial year, while our statutory income fell by 11%. We were only able to raise our voluntary income by 7% over that period, despite the brilliant efforts of the public to make donations to Marie Curie. I know that many of you came along to our great Daffodil appeal in Parliament last month to try to give a boost to those efforts, and we are enormously grateful. The fundraising is brilliant, and it is great to have the support of the British public, but we need a bit more support from the Government to plug the funding gap.

Q13 **Chris Green:** Thank you. Dr Abbas, the sense I have from local hospices is that when the integrated care system was put into place, even though the people in the hospices are the same and even though the people delivering the NHS services and the management structures are basically the same people, fundamentally the relationships were broken, and they have not yet been re-established in terms of the funding relationship. Is that fair comment?

Dr Abbas: It would be fair in some areas. In some areas there would be good practice. Let me explain where I work. As I said, I work in west Essex. One of the privileges of working there is that, broadly speaking, we serve three district councils. Harlow is not such an affluent area, but if you go northwards towards Uttlesford, it is a very affluent area. If you go



towards Epping Forest and the Chigwell area, they are totally different demographics.

Basically, the beauty of palliative care is that the models we take should be demographically assessed. Local needs will always need to feed into how we make our strategies. We should take good practice from here and there. Your question was on the relationship with the ICB. When we have a bigger area, it is an effort to explain to them what happens in Harlow when they are based somewhere else. What happens in Uttlesford takes effort and time. Data is required to back up the strategy. When you have developed a relationship with a particular CCG or area, you have already crossed that bridge. Now you have to go back to that point. I am not saying that the relationship is broken, but it is a lot of effort.

Q14 Chris Green: Different parts of the health system have their voices on the ICB. Are you confident that you have the voice you need on the integrated care board?

Dr Abbas: People from palliative care might be there, but in my experience in the east of England the majority of ICBs are led by people who, to be honest, have not worked in palliative care. They are fantastic GPs who have very good connections, but it is a matter of going back to them and working with them. Yes, it is not as strong a voice as it used to be.

Q15 Chris Green: The expectation is that in the very near future that relationship is going to be stronger. You will get the funding, but are you confident that that is going to be happening in the near future?

Dr Abbas: It will be a lot of work with colleagues to do that. There are other pressures as well, we have to remember. I come from a medical background. I have been at St Clare since 2000, and the model of palliative care has changed in front of me many times.

We have to look after end of life care, the cancer model, that type of thing. We have always said that we are not just about cancer, but the reality was that the majority of the patients were. In the last few years there has been a lot of emphasis, as I have already said, on frailty, dementia and non-cancer diseases. We need to develop expertise that way. It is not just about the core clinical service. It is about employing people who can do their job, employing people who can train to do that and getting resources to do research in your own area. You are being funded only for in-patient unit beds or community nurse specialists, but we have to spend money to do those other things as well. The compassionate neighbour model comes in. You have to look at that.

In my experience, we are talking about a very good model when we can support A&E. Why do people go there? Quite often, there are physical issues. My experience tells me that quite often it is not just about physical care. I take time to think about the last time I saw somebody dying in excruciating pain. I remember a lot of bad deaths which



happened because of the lack of psychological support for the patient and the family. That has not been seen as a priority. Hospices can do that type of work, but that is where you need support. You need to strengthen the resilience of the community. In the “Ambitions” document, which came out in 2015, we talked about every community being prepared to help. I don’t think we have invested there at all.

Chris Green: Thank you.

Chair: That’s really good. Thanks for that exchange.

Q16 **Mrs Hamilton:** I want to discuss what you talked about, Ruth, which was around the charity side of things. I do not believe it is as equitable as it should be. I am from quite a poor area of Birmingham. My background is health—I am a nurse. As you so eloquently talked about, when I worked as a nurse, we worked for the local authority but went into different palliative care institutions. We followed the patient in and out, but things have changed quite a bit.

My question is about charitable funding. If you live somewhere like Surrey, you have lots of rich neighbours. They can really support what a hospice is trying to do. If you live where I do, where the hospice is doing a great job, they cannot raise the type of money that they can raise in other parts of the country. What do you believe we can do to bring more equity into this area, because it is very unfair at the moment? I will start with you, Toby, for Hospice UK.

Toby Porter: I am so glad that you brought this up, Paulette. I know Addington. I was the chief executive with Acorns Children’s Hospice in my last job, which serves the kids in your area. I know John Taylor Hospice, as does James. Generally, the Greater Birmingham area is such a concern at the moment. Hospice finances are disastrous over the last couple of years. The John Taylor Hospice that serves closest to your community—

Mrs Hamilton: Yes, I live round the corner.

Toby Porter: Their finances are so tough. In fact, I was just jotting down the hospices that serve closest to the constituencies that Members here are from. You see the inequality for the reasons that you say. Logically, if statutory funding is insufficient, as a broad rule—it is not a scientifically exact rule in every case—there is an absolute correlation between the wealth and economic resilience of a local community and the degree to which a charitable hospice can still provide a full service with, if you like, the dismal statutory settlement that many of them have.

Going around the table, Chris, hospices like Willowbrook are just about managing and serving that area. Naomi House is well supported, Steve. It is a much-loved charity in your constituency. Rachael, your children’s hospice is Martin House. St Leonards has a lot of support from a community that is able to fund them very generously, but not in Halesowen or Erdington. Even with the five of you here, your hospices live such different realities. It all comes down to an obvious and logical



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difference in the ability of a community to fully fund a hospice service where the statutory settlement is inadequate.

Property prices are a huge variable. If you look at the average house price in Erdington versus Winchester, and you think that 15% of hospice income comes from charitable gifts that tend to be tied up in the sale of the house of a legator, that is the reality. The status of charity is a wonderful thing. The support that hospices enjoy from their local community is wonderful, and your local community in Erdington does not appreciate or support their local hospice any less generously than Steve's in Winchester. It is just that the ability to make really large donations to fund an all-year round health and social care service is different.

We celebrate our status as charitable hospices. We celebrate the flexibility and the ability to innovate. That is the challenge for the NHS and the ICBs. At the moment in the UK this year, 656,000 people, plus or minus, will see the end of their life. In 2040 that number will be 790,800, so that is an extra 140,000 people. Together, we have to work out what kind of death we want people in this country to have.

It is great to be a charity, but going back to the first question that Steve asked me, I do not think ICBs yet really understand the charitable sector. I will give you some very quick examples. On workforce planning, whether it is the health and social care workforce planning initiatives, which are hugely important nationally, or whether it is national or local, the 16,000 clinical and care workers in the hospice workforce are not included in those strategies.

I don't think that ICBs understand charities and I do not say this light-heartedly. Many ICBs have deficits year in, year out. I don't think they understand that a charity board does not have that luxury. The charity board will simply say, "If there's not enough money coming in, you have to solve the problem by reducing your expenditure." Somehow, because we are charities, people do not understand the deep professionalism in the hospice sector. I am glad you raised this, and I am so glad to have the chance to say that things in Birmingham are so tough at the moment. I am really worried.

Q17 Mrs Hamilton: I will ask Ruth, because you made a fantastic start, and then James.

Ruth Driscoll: Thanks, Paulette. I agree with Toby. The simple fact is that over-reliance on charitable fundraising, as opposed to funding from Government and integrated care boards, means that communities that are wealthy enough to fundraise for a local hospice typically have better services in their local area. It is important to name the problem clearly.

We know that about 90% of the deaths that take place each year in the UK require palliative care, yet our best estimate suggests that about one in four of those people are missing out on that care. Let's name those groups. The clearest example of inequality in access is people who are



living in poverty and deprivation. Currently, about 90,000 people are dying in poverty each year. They are in the communities that struggle most to access the care and support that they need from hospices when they are dying at home. As a result of that, they are often the group who call an ambulance and rush into A&E, in crisis at the end of their life. Living in poverty is associated with an increased risk of dying in hospital rather than in your community, at home with your loved ones. There are more emergency admissions in the final months of life. Overall, people living in the most deprived areas, like yours, Paulette, are 33% less likely to be able to die at home with support from their local hospice or the NHS.

We know that other groups are missing out. You have already mentioned one of them. People who are living with non-cancer conditions such as dementia, motor neurone disease, heart failure or diabetes tend to get a worse deal. People living in rural and deprived areas struggle to be able to reach a local hospice or NHS services. Minoritised ethnic communities get a very bad deal at the end of life as well. Other groups who have experienced disadvantage throughout their lives would include people living alone, people with learning disabilities and people who are homeless or who are in prison. All of those groups are missing out badly on good-quality palliative and end of life care.

Just like the NHS, at Marie Curie, as a hospice charity, we are trying to reach those people, but we just do not have enough Government funding to enable us to do that. In our five-year strategy we have a goal of doubling the number of people we support through our services. We need your help to try to get there and to reach those under-served groups, especially in communities like your constituency, Paulette.

Q18 Mrs Hamilton: Thank you. James, what about when it comes to children?

James Cooper: It is really important that we start focusing on children, young people and their families. They need care and support from hospital services, community services and children's hospices. The bulk of children's palliative care is provided by the NHS supporting families at home, providing 24/7 care.

ICBs have the opportunity to implement the policy framework that I mentioned earlier. There is a service specification that NHS England set out around children's palliative care. If they put that in place, looking at the range of services they need, across symptom management, short breaks, emotional and psychological support and advanced care planning, there is the opportunity to make sure that children and families get that care.

There are some really good examples across the country where it is working. In the east of England, for example, there is a 24/7 end of life care service for children and young people, which provides care and support at home, supported by specialist paediatric palliative care



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consultants. That is a standard set out by the National Institute for Health and Care Excellence. It has had some interesting outputs in reductions in contact with GPs and also hospital admissions.

Q19 Mrs Hamilton: When it comes to charity, I believe children do better because people say, "Ah." In very difficult areas like my own, do you believe that we should allow this sector to live or die by the charity income they receive? I will let you finish and then ask the others.

James Cooper: I agree with everything that Toby and Ruth said. It is not acceptable that we are relying on charitable donations to fund lifeline crucial care that it is a statutory duty for ICBs to provide. The majority of funding for children's hospices comes from charitable donations. A large proportion of that is from retail. We need to make sure that equity is available right across the country.

In order to make sure that happens, we need to make sure that the Government review the way they fund children's priority care at the moment; committing to the £25 million children's hospice grant for the long term would be a really important start. They need to start holding ICBs to much greater account for the way in which they commission children's palliative care, including mandating planning guidance and asking the Care Quality Commission to examine the extent to which ICBs are commissioning this care as well.

Q20 Mrs Hamilton: Brilliant. Dr Syed, do you believe that hospice care should live or die by the charity donations they are receiving at the moment? The other funding is a myth.

Dr Abbas: Your question is "should". It shouldn't, but part of the freedom that hospices have are those charitable donations.

Q21 Mrs Hamilton: Do you not agree that that should be the icing on the cake?

Dr Abbas: Icing on the cake. That is a good point.

Q22 Mrs Hamilton: It should not be where their fundamental funding is coming from.

Dr Abbas: It should not be. The core clinical services should be funded by Government, yes.

Q23 Mrs Hamilton: I am going to ask you the last point, Toby, on the same subject. As Hospice UK, what would you like us to tell Government if we were going to go away with a point today around the charitable bit of the funding that your organisations receive at the moment? What would you like us to tell Government?

Toby Porter: To acknowledge that we cannot rely on charity to reach all communities in all parts of the UK. Obviously, it is the poorest and most excluded communities that have the most to gain from a better statutory settlement.



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By the way, to give a perfect illustration, Paulette, of the “icing on the cake” approach, which I thought was a really interesting model, just over the water the Government in Dublin announced in December that they were going to increase the funding for their charitable hospice sector from just under 30% to about 93%. They did that by agreeing with the hospices what clinical and care staff they needed to provide a core service, and what staff they needed to support that core service. They then said, “Right, we now consider these employees as delivering services on behalf of the state and we will fully fund them. We’ll fund their sick leave, their maternity leave, their pension provisions and pay increases, but we still respect the charitable nature of your hospices. We will leave you in control. We’re not after your independence, but we are going to pay for the delivery of that core clinical service.”

That has meant that the hospice leaders now, for the next few years, can use their charitable income to provide additional services and to invest in their buildings and their equipment. They are free of the existential fear that so many hospice CEOs are living with now, which is, “I cannot see how I’m going to be able to pay my core staff to deliver my core clinical service.” That would be my thing.

Q24 Mrs Hamilton: The very last point is to you, Ruth. It is the same question. I am very against the fact that we are using charitable money to prop up these organisations. If we are saying that we are the NHS and free at the point of delivery from birth to death, we need to follow that through to ensure that when you get to a certain part of your life, you are not then just relying on people giving funding to ensure that you have a good death. What would you like to say as the last point, to ensure that we really take this on board? Could you be quite brief, as I want to hand back to the Chair?

Ruth Driscoll: We think that everyone has the right to the best possible care at the end of their life. Too many people are missing out on that care at the moment. The NHS promises to care for people from the cradle to the grave. The grave part is not being properly addressed through Government funding for hospices like Marie Curie right now.

We want to see a new funding model for palliative and end of life care that allows for the full costs of delivering what should be core NHS services to be covered by statutory funding. That is what we need to see. We also need a national delivery plan for palliative and end of life care from Government. The new funding model should definitely be at the heart of that.

Mrs Hamilton: Thank you all so much. I will hand back to the Chair.

Q25 Rachael Maskell: Can I start with you, Toby Porter? Yesterday I heard the news that St Leonard’s Hospice is expected to get a 1.2% uplift. I was told informally that it will only be £8,000, which is 0.6%, despite St Leonard’s carrying an £800,000 deficit the previous year. The law changed in 2022—it does not feel like it, but the law changed. How do



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you want to see ICBs being held to account for the decisions they are making around funding palliative care?

Toby Porter: That is a very good question. There are lots of examples like the St Leonard's situation. It is an outstanding hospice, and they deserve to be properly funded because they do so much for your community. The problem at the moment, and what we see, is that NHS England and ICBs are slightly passing the buck between each other. You saw how much support there was in Westminster, but the debate ended by saying, "Well, look, we have a devolved system and ultimately these decisions are made by the ICBs." The ICBs say, "We would love to help you. We recognise and truly value your partnership and everything you do for our local community, but there is no money and we don't have anything." The two are dancing around one another. As a hospice, you feel like you are being bounced from pillar to post, where the obvious political will that exists to support the sector is not being translated into concrete, material outcomes that support the delivery of services.

I urge Committee members to think about what we can do to be much more directive about NHS England and ICBs coming together and working out what we are going to do for end of life care in this country. It is the laggard. It is the part of healthcare that is always last to be thought about and last to be resourced. There may be very good reasons in terms of not liking to think about death, but when you look at the demographic change that the UK is in the midst of, that is not a very practical strategy.

We need someone to take responsibility for better outcomes. I don't even think, by the way, it should be just saying, "How are we going to do better for hospices?" If your focus is on how we are going to deliver better end of life care in the UK for all communities, in the end there is no scenario in which people are not going to look at the hospice sector as something that can be supported to deliver more for the Government. We need solutions. For example, in 2011, NHSE made a promise that there would be a tariff introduced for end of life care that could form the basis of a rational evidence-based funding approach for what preceded ICBs to support their hospices. It has still not been produced. In 2014 and 2019 there were flutters of activity, but again nothing was the outcome.

Right now, we are at the beginning of a 15-year increase in death and dying in the UK. Because of its budget pressures, NHS England has just had to downsize its dedicated end of life care significantly. It feels to me that demographic logic, political will and bureaucratic decision making are moving in different directions. It is like two parts of the iceberg have come asunder and are drifting off in the wrong way. They need to be brought together. That is what I would say.

Q26 **Rachael Maskell:** James Cooper, can I turn to you? With regard to the children's sector, how would you respond to that question?

James Cooper: I absolutely agree with Toby. We see a huge amount of variation in ICB commissioning and funding for children's palliative care.



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We are seeing some improvements in the extent to which NHS England holds ICBs to account. I believe that it is putting palliative care into its quarterly reporting framework, which is positive, but ICBs have the autonomy to make those decisions themselves.

As a start, NHS England needs to understand the extent to which outcomes are being met for children and young people. Then it needs to understand the extent to which ICBs are actually specifying those services. We have been able to do this through freedom of information requests and surveying children's palliative care networks, but it should not fall to charities like us to get that kind of information. The Government and NHS England should understand what is being commissioned and provided in the system and whether outcomes are being met.

There is much more that they could do to hold the system to account. As I said, they could mandate the Care Quality Commission to examine the quality of work that is being done at ICB level. They could put it in the planning guidance and in their mandate to NHS England. As I mentioned earlier, there is a need for ICBs to work together at regional level, because of the very small numbers of children who are seriously ill and need this care. There are no incentives or levels of accountability in the system at the moment for them to do that. While we see some good examples at ICB level, there is far too much variation that we need to overcome.

Q27 Rachael Maskell: I have a slightly different question for you, Dr Abbas. We see palliative and end of life care patterns changing. In particular, there is a movement towards hospice at home. Obviously, people will also die in other locations, such as care homes and prisons. How do we ensure that the funding of the integrated service with other health professionals is adequate? We have been talking about the dance between NHS England and ICBs, but we could also see that between the devolved provider of primary care and hospices. How do we ensure that there is better integration and understanding of who is funding what to give quality end of life care?

Dr Abbas: Part of the answer is what you have already said. It is better integration. We have talked about the different challenges. At the moment, if we speak to the ICBs or NHSE, the understanding of end of life care models has changed, as you said, and where people are dying has changed. We have talked about people dying in care homes and at home. Some funding and thought needs to go towards training in those areas. Hospices, as specialist providers, can contribute to that training.

At a simple level, there have been discussions about salary uplift for nurses, doctors and consultants, for example. That information never goes to ICBs or NHSE, so we will never receive that uplift. That invariably means that we will have to ask the question, "What do we cut now to legally provide these things?" You said that people are dying in different



areas and we need to look after that. Invariably, what gets cut down is training. That cuts down integration, which directly affects patient care.

Q28 Rachael Maskell: Can I check something? When you say training, is that so that a district nurse, for instance, will have the competencies and the confidence to administer care at a level that provides the palliative support that the patient needs?

Dr Abbas: It is not just the district nurse; it is the primary nurse. For example, even if you work at the university level and try to train junior doctors and junior nurses, you have to remember that a lot of our workforce is trained abroad. When they come here, we need to uplift and upskill them, but a lot of our commissioners think that they are already trained, so there is no need to do that type of training. I am sure all of us have experienced many training days that we organised when 10 people booked and two people turned up, because the work pressure was so immense on the ground.

You asked how we can integrate and provide care in prisons, care homes and other places, such as learning disability centres. The other part of the spectrum is elderly people living alone. They are being left out big time. Their needs should come in, through good training, good working together and integration—again, with the community. The uplift in funding definitely has to be for core clinical care, but it must also be about training and ongoing research into the needs of our demographics. How many people lived alone in 1990, as compared to now? That has changed. How many people were dying with learning disabilities? We have talked about people having transitioned from childhood to adolescence. Now, with good care, they will be seen in the adult hospices. We will need to look after them. All the research and education also needs to be taken into consideration when we are making recommendations about funding. That should be taken into account.

Q29 Rachael Maskell: Of course, we have seen poverty levels rise as well. That goes back to Paulette's points.

Ruth Driscoll, can I refer to some evidence that you put forward? You believe that the demand for hospice provision will rise by 13% over the next decade. There is data that says that it will rise by 25% by 2048. In setting a funding pathway to the future and determining the responsibilities on ICBs, while still trying to see the NHS as having some responsibility in Whitehall, what do you want Ministers to consider to ensure delivery, for the longer-term future, of the funding that is needed at the point at which patients receive the services that they should get?

Ruth Driscoll: One issue you touched on there, which I will pick up on, is workforce costs. Part of the new funding model that we are seeking from the Government is to ensure that contracts or grants for palliative and end of life care that are given to hospice charities are uplifted in line with inflation and cover the true costs of delivering those core healthcare services.



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A key part of that is ensuring that we can recruit and retain the workforce that we need to provide care for which demand is rising very fast because our population is ageing. Marie Curie is famous for our nurses. The work that they do is amazing, but covering the costs of the nurses is just one part of the staffing costs that make up a big proportion of our overall costs as a charity. We are recruiting and seeking to retain the same sorts of staff that the NHS is often seeking to recruit and retain. You will know that that recruitment pool is under a great deal of pressure now.

To illustrate the challenge, an agreement was reached in March between the Government and the unions on the NHS pay award and Agenda for Change. We fully respect the right of our NHS colleagues to be paid a fair wage for the work that they do, but this had the unintended consequence of placing some unplanned and unforeseeable pressures on the budgets of charitable hospices such as Marie Curie. The pay award last year of 2%, alongside the lump sum covid bonus and the proposed consolidated increase of 5% for Agenda for Change, led us to face an immediate requirement to find £3.6 million of additional funding, on top of announcements that we had already made about pay to our own workforce. The recent announcement that the non-consolidated payments would be made to non-NHS providers, including some charitable hospices that were matching Agenda for Change for their own staff, was really welcome, but it took a long time for the Government to make a decision on that. Those payments cover only part of the additional costs that are being incurred by hospices to have the right workforce in place.

Let's be clear: this is one part of a much bigger problem around workforce. Currently, the NHS national workforce plan does not give consideration to hospices and the role that they play in palliative and end of life care services. That is why we struggle to recruit and retain the right workforce. That is why we have some of the training challenges that you mentioned, Dr Abbas.

It would be brilliant if every health and care worker, regardless of whether they work for a hospice charity or another organisation, could have good-quality training in palliative and end of life care. At some point in their career, all of those workers are going to be supporting someone through the end of life. Much greater attention is needed to the workforce challenges that hospice charities are facing and on how to make sure that palliative and end of life care is part of wider workforce planning for the NHS and for social care.

Toby Porter: We did some media work on this question, which illustrates some of the problems that we have for our hospices. We illustrated that another £150 million would have to be raised for the hospice sector to meet the pay awards. I remember that the Department of Health and Social Care issued a press statement in reaction to what we were saying. It said, "Hospice charities are free to pay their staff whatever they like." I thought that that was a real shame, because the Department of Health



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and Social Care knows perfectly well how difficult it is to recruit clinical staff at all levels.

That is illustrative of the problems we have. We are not given the money, we complain about it, and then we are told, "You're charities. You're free to pay people whatever you like." We are providing super-specialty palliative care services in many hospices, at a level and complexity above what you would get in a hospital. They are not people who just turn up for a day's volunteering: "How can I make myself useful today?"

Chair: That is brilliant. Finally, James Morris.

Q30 **James Morris:** I want to probe a little more about the workforce challenge you are talking about. Mr Porter, you said—and Ruth said the same—that the NHS has its long-term workforce plan. Were you consulted at all when the Government went through the process of thinking through the long-term challenges for the NHS workforce?

Ruth Driscoll: There was a public consultation on the NHS national workforce plan. We submitted evidence from Marie Curie—

Q31 **James Morris:** You were not specifically approached for your view by NHS England.

Ruth Driscoll: No. We were not invited to meet individually or to give evidence in a more formal way. We did a written submission. Our submission focused very much on the fact that hospice charities and palliative and end of life care needed full consideration, because we are non-NHS providers. We are charitable providers.

Q32 **James Morris:** Yes. Drilling in, what are the key drivers of the workforce challenge that your sector has? The NHS workforce plan, which we are talking about, looks 15 years into the future, looking at demand and so on. What is the nature of the workforce challenge over the next decade and a half? I am looking at you, Ruth, but perhaps Mr Porter could start.

Toby Porter: Chris Whitty did a recent report for you all on the ageing population in the UK. He used visualised data very effectively to illustrate how the workforce are moving away from the same areas that people who are ageing are moving into. There is definitely a phenomenon at the moment of people retiring to communities. That might be pushing up house prices, so people who are working in public sector-type professions are moving out of those same communities. Chris Whitty made some suggestions about decentralising training and providing routes at all levels.

I highlight what Ruth says. Actually, it was even more frustrating, because we said consistently throughout our response to the consultation how important it was that the hospice sector and other health NGOs or voluntary sector organisations were included in the health plan. We said, "Please write this for us, too, because we see our workforce as part of your workforce." That was not actioned. It is very frustrating.



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Dr Abbas will probably have a more informed view on this, but I would say that the most important thing is that we need to offer training in palliative care at all levels, both in primary healthcare and in specialist care. There is a very worrying lack of consultant cover in adults' and, particularly, children's palliative care, which has the potential to be catastrophic if steps are not taken to reverse it, but I defer to Dr Abbas on that.

- Q33 **James Morris:** Can I ask you one follow-up? When you talk about training in palliative care, do you mean training in palliative care for consultants and others working in the NHS itself?

Toby Porter: Yes, to make sure that it is integrated into all training.

- Q34 **James Morris:** It is not a nice word, but, as you mentioned, one of the challenges is that there is a kind of cannibalisation of staff. You are competing, as it were, in a market where the NHS is looking at the same people. Is looking at a more collaborative model one way of solving the conundrum?

Toby Porter: A hundred per cent. There should be a seamless ability to move from the voluntary sector back into hospital or back to a GP surgery. The pension plan changes already facilitate that. That was a good example of intelligent policy that removed an enormous barrier to people being able to have portfolio careers within the NHS and voluntary healthcare sectors.

- Q35 **James Morris:** That is really helpful. Dr Abbas, you said that the model of hospice care—the notion of palliative care—is changing. Historically, it referred to end of life with cancer, but there is a lot of other presentation now. You talked about frailty, dementia and isolation. What are the implications of that change for the workforce? What additional skills are required?

Dr Abbas: I used the word “changing”, but maybe I should have used the word “evolving”.

James Morris: Evolving?

Dr Abbas: Yes. We have talked about doctors and nurses, but when we are talking about the things we need to look at, we need to have much more emphasis, which we did not have in the '90s, on allied health professionals such as physiotherapists and occupational therapists. Colleagues have better data than I have, but if you look at the national hospices, the majority of contracts will not hold commissioning for those services.

Secondly, there is a lot of emotional and psychological burden that comes for the 95% of people who will require palliative care, but even the last 5% still require bereavement support. We need to have some understanding of how to commission the counsellors, social workers, chaplains and psychologists who can look after those people. We are



looking at an extended workforce, not just developing the workforce. What is happening is that we are losing even the existing workforce—the doctors and nurses.

You talked about the training model. I will talk about specialist palliative care consultants. We have moved from five years of palliative care training to changing the shape of training. Basically, that means that for one year you will work in an acute hospital. There is another thing I worry about. I work in a hospice that has eight beds. The majority of hospices in the country have 12 beds or fewer, if I am right. If I am a doctor training today in acute medicine and palliative medicine, where am I going to take my specialty? Invariably, I will be working in an acute hospital. The competition—your word—is going to get worse and the small hospices will suffer. There are already hospices in the country that do not have a consultant.

Q36 **James Morris:** What is the solution to that?

Dr Abbas: The smaller hospices—all the stakeholders—should be made part of the consultations. We send our consultations here and there by writing, but we are not all around the table. When the shape of training changed, all the small hospices said, “What is it about?” It was still changed. The same happens with specialist nurse training. I know that we are short of time, but I talked about this because I am very passionate about the workforce.

Q37 **James Morris:** That is very helpful. James, you talked about the significant increase in the number of children coming into the hospice sector. We have been talking about the workforce challenge. When it comes to providing psychological support for the child, the family and so on, do you see a similar challenge in your bit of the sector, if that is the right way of describing it?

James Cooper: Very much so. The children’s palliative care workforce spans the NHS and the voluntary sector. At all levels, we are seeing shortages at the moment. Palliative care is a key skill that needs to be shown by a number of different paediatric professionals, but they need support from specialists. For example, paediatric palliative care consultants need to undergo two years of GRID training, overseen by the Royal College of Paediatrics and Child Health. We have just over 20 whole-time equivalent consultants across the UK at the moment. The RCPCH has estimated that we need somewhere between 40 and 60. Nursing, as I said, is crucial. We have around 900 community children’s nurses employed by the NHS in England at the moment. RCN figures suggest that we need about 5,000. There are shortages of allied health professionals and social workers.

There are steps that can be taken immediately to make the most of the existing workforce. That is where ICBs and NHS England come in. We should be looking at regional areas and thinking about things like operational delivery networks to organise those services. In the long



term, we need investment in training and education. It is about making sure that that is in the workforce plan. For relatively modest amounts of money, we could increase the number of training places for specialist consultants and the number of community nurses who have the skills and experience to provide palliative and end of life care.

There are a number of calls on this Committee when it comes to increasing the workforce, but for this particular group of children and young people, time is short. They do not have time to wait. The title of our recent report, "Short Lives Can't Wait", makes the point that if we make these investments, we can make sure that children and young people who are at the end of life and need crucial care can receive the care that they need.

Q38 James Morris: We were talking about the NHS workforce plan and the way it worked. Were you similarly not formally approached/involved in the development of that plan?

James Cooper: No, we were not. We completely echo the points that Toby and other panellists have made about the extent to which the voluntary sector is reflected in those kinds of workforce plans. It is not just the latest workforce plan. It is historical. The voluntary sector is a crucial part of our health and care system. We need to understand the vacancies there and the work that needs to be put in to make sure that there is a workforce with the skills and experience there, too.

Q39 Chair: Obviously, we will write a letter to the Minister off the back of this session. If you have not made the money shot you would like to leave us with, please raise your hand and make it.

To conclude, can I put a question to Toby Porter? When we did our assisted dying and assisted suicide inquiry, we were due to visit Winchester hospice, but we didn't. In the end, we visited a hospice here in London. Winchester hospice is not unique, but it is quite unusual, in the sense that it is on a trust site. Charitable fundraising was used to build it, but it is staffed by trust staff. In the transition I was talking about earlier, between different levels of care—from young people, through teenagers and older people, into end of life care—it really helps them to look after a wider range of patients, because it flattens the pathways of care. Looking at the future, are we likely to see more of that?

Toby Porter: It is certainly a very plausible model. There are about 15 such hospices that are fully staffed and managed within a trust—where a charity exists, but focusing on Paulette's icing on the cake-style activities. We have approximately 194 charitable hospices in the UK. They are all very different, so a one-size-fits-all approach would be difficult to advocate at this point in time. For some hospices—particularly in more economically challenged areas, although I note that this works very well in Winchester—a model where the core clinical workforce is paid for is



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absolutely the way that we need to go in many parts of the country to safeguard these essential services for the future.

- Q40 **Rachael Maskell:** On the back of that, although it is less about funding, can you see greater integration as a result of that across primary and secondary care, as well as within palliative care?

Toby Porter: Yes, I think you would.

- Q41 **Chair:** Anybody else?

James Cooper: As the Minister said in her response to the debate last night, the Government are limited in terms of long-term spending decisions by the fact that we are due a spending review in the autumn, after the general election, potentially. But in this particular group of children and young people there are children receiving end of life care now who are not getting the choice between home and hospice care, if they do not want to receive care in hospital. We appreciate where we are in the electoral and fiscal cycle, but it is within the Government's gift to commit to the children's hospice grant for the long term. That is a political choice. We would like to see that commitment urgently.

Ruth Driscoll: My final point is one that we have not addressed directly. We have chatted about the important need for more Government funding, but I want to make clear that it is a tough old world out there for our fundraisers right now. Charity giving is moving to a model where it is heavily reliant on a smaller number of donors. Retail is becoming less and less viable, because the costs of utilities, rents and wages are all going up for charity shops.

There are things that the Government could do to make charitable fundraising easier for hospices. One would be to make gift aid much more accessible and easy. Maybe it could be an opt-out rather than an opt-in model. Another thing would be for them to open up many more conversations with philanthropists and the private sector about a giving, caring and compassionate society. Another would be to tackle the probate backlog, which is causing a big challenge for Marie Curie in bringing in the very generous legacies that people leave to us at the moment. There is a big backlog in the courts, which means that there are long delays in that money reaching us as fundraised income. Lots more could be done to make charitable fundraising easier for charities such as Marie Curie.

- Q42 **Chair:** That is very useful and helpful, with some good nuggets in there. Dr Abbas?

Dr Abbas: Most of the points have been made. As Ruth said, it costs money to raise money. When you are trying to employ good fundraisers, you need to spend money there. When you are a small hospice based on one site, you must have equity in what you offer your clinical colleagues, as well as non-clinical colleagues. That costs money.



Clearly, we all need to decide about care from cradle to grave. The last point that I want to make is that in the long run this affects the morale of the doctors, nurses and other clinical colleagues who are working there. Are you really being taken seriously when you work here? The people who come into hospice care are all passionate. I know that my team are working there because they want to make a difference. When these sorts of messages do not go out very well, that directly affects how people have the oomph to get up in the morning and come to work.

Q43 **Chair:** Lovely. Mr Porter?

Toby Porter: I have a last statistic. It was quoted a lot yesterday. This year, we estimate that hospices will have a collective deficit of £77 million. On the train, I was looking at some earlier years. If you take out 2020-21 because of the pandemic, which so skewed income and expenditure patterns, and pool together the five years of 2015, 2016, 2017, 2018 and 2019, the hospice sector made a surplus of between about £65 million and £70 million. In one year, we have lost more money as a sector and have a bigger deficit than in five normal years pre-pandemic. Thank you very much for having us here today. That is where we are. It is a very urgent time. We need a serious conversation about how we fund palliative care.

Chair: Good. I like those little Springer's final thoughts. As they say, "Look after yourself and each other." I thank James Cooper, Ruth Driscoll, Toby Porter and Dr Qamar Abbas for their time. That concludes our session.