

The 'perinatal hospice' and the dignity of the dying infant

Uncorrected transcript¹ of presentation by Dr Sylvie de Kermadec, obstetrician-gynaecologist working in France, given 18 June 2012 in Oxford at a conference on 'Human Dignity in Healthcare' co-sponsored by Blackfriars Hall and the Anscombe Bioethics Centre.

Abstract

Every human being, including the unborn child, has full human dignity, even if his or her body, health or intelligence is seriously impaired. Although the protection of children generally is seen as a priority, respect for unborn children is often 'forgotten'. When a severe genetic or medical anomaly is discovered during the pregnancy, it is as if the dignity of the child disappears or is denied: the medical team communicates partial information to the parents, mentioning only medical considerations, which generally leads to the termination of the pregnancy. This causes severe suffering for the parents, not only at the loss of their child, but also because their child's dignity has been denied. It is then very difficult for the parents to heal. Working from our own experience, we propose a different approach: helping the parents to realize that their child is a true human being, with full human dignity, and that it is possible and brings peace to treat him or her according to that dignity; that is, to accompany the child until natural death, even if this death takes place just after natural birth. Examples and principles of this very special way of caring for the unborn, or soon-to-die newborn, are given.

Presentation

I will try to share with you some of my experiences of accompanying families confronted with the diagnosis of a severely disabled child. This was one of my main tasks in the hospital where I worked for several years. At the time I began to do this it was very, very unusual - I would say very abnormal - to suggest such a course of action to the parents, when the diagnosis was that the baby would be very sick and would probably die after the birth. It was a very difficult thing to accompany parents in this particular way. It was considered to be very cruel not to accompany the parents very quickly to a termination of the pregnancy, and it has been a great pleasure and surprise to me to discover after twenty years of this work, not only by me of course, but by other teams, that this proposal of continuing with the pregnancy in such circumstances was becoming seen as natural and as a serious option and not something completely extraordinary. This is a sign of hope, because I never would have thought it would be possible, and I went on in this way knowing that I had to do this and that I would probably be criticised for it for my whole life - which did happen - and that this option would never, ever be seen as a serious one, or accepted by the medical community. So this is a message of hope: that we must never give up, because sometimes things work out, even when we lack hope ourselves. That is why I wanted to give you some very simple details of how it is possible to work with parents and to see the unborn baby as a human being, with full human dignity.

¹ The abstract was submitted in advance by Dr de Kermadec and so can be quoted publically, but the text of the presentation has been produced using the audio recording and has not yet been agreed with the author.

As you can imagine it is an extremely painful situation for the couple to be confronted with the diagnosis of a severe abnormality in the expected child. The suffering and distress is extreme and in this situation the gynaecologist is often not able to help the parents to recover from this terrible news. They do not take the time and thought necessary to help the parents to make the best decision. More often the obstetrician gives the deeply disturbed parents the advice he thinks is right; that is, to have an abortion as quickly as possible. Generally the term used is 'therapeutic abortion'. It is absolutely not therapeutic, because it is not therapeutic to cause the death of a patient you cannot take care of. So now in France this is called 'medical' abortion, but that is not the best word either, because doctors should not kill their patients when they cannot cure them.

Many couples can testify to this tendency for the physician to push them, even to 'force' them, into having an abortion, most of the time extremely quickly. I would like to say a word about these doctors: a compassionate word, because I cannot believe that they want to be cruel to the disabled baby or the parents, but they just cannot imagine that it would be possible for the parents to choose to carry on with a pregnancy, sometimes for several months, only for the baby to die a few hours after the delivery. Anyway, I can tell you that I would never have thought it possible that this would be a live option.

These doctors fight for abortion when the baby is very severely disabled for several reasons: their pride and their lack of humanity. First, they cannot imagine making this decision in their own family, so they deny their patients the right to a different point of view to the one they would have taken themselves. Secondly, it is the joy and pride of our professional work that the babies we normally deliver are well. Sometimes these doctors feel that it is a personal offence to deliver a baby who will soon die. They see it as a personal defeat. I will confess something that you know very well: obstetricians sometimes - I might say, often - believe a little that they are God. We are confronted with life and we think we give and decide on life and forget that we have to serve God through our patients. Doctors are very surprised when you tell them it is not professional to transfer their own views to their patients and not respectful of their patients' freedom for the doctor to make the decision for them, as Dr David Jones' paper at this conference made me understand very clearly.

How can we respect the freedom of the parents, knowing it may lead to the birth of a severely disabled baby who will need palliative care? I will describe special points in the process and the importance of certain times: the care of the mother during the pregnancy, and although this will be very short, the delivery and the hours until the baby's death.

This is not a paper for professional people: everyone can understand it, because I think that a new way of looking at and considering the baby who is to be born, even if he is going to die, is good for practitioners and for everyone - the parents, the politicians and everybody - because if we change our outlook about this, we can make better choices.

How do you tell the parents that their baby, the bearer of all their hopes and happiness, is so ill that he will not survive after being born? It is always very painful for everyone: the parents and the doctor. One important thing is to speak of the 'baby'. Many parents say that at the moment of the diagnosis the word 'baby' disappears completely from the conversation between parents and health professionals. They feel as if the existence of the child was suddenly denied, as if he had never existed. Only the abnormality exists. But the parents know very well that they were expecting a baby and feel very hurt at this denial of his

existence. A mother said to me: 'it is as if, after the abnormality, the doctor killed my baby a second time.' Of course we describe the reality of the abnormality with honesty, explaining that the baby does not suffer as long as he is in the womb. We describe exactly what will happen and do not lie about the reality of the defect. The second most important thing is to encourage the parents to take as much time as possible before making a decision and never to push them. I have often seen parents encouraged to have an abortion on the same day as the diagnosis was made. Why is it so important that the couple takes time? It is because of the different phases of reaction that each parent goes through and because they have to consider different points of view concerning who their baby is. There are different phases of psychological reaction: when you are very stressed, when someone you love dies of cancer or in an accident or you receive bad news, you go through several different states of mind, and this happens of course when a prenatal abnormality is discovered. The parents will have to go through successive states of mind. First, consideration of the diagnosis. It is impossible to react or to think. It is as if you have been struck by a poleaxe. Then one goes through denial of the truth. The parents deny the disability, in which they cannot believe. Then comes anger - revolt against what is happening. At this period very strong or violent words are often spoken by the parents. But we must be careful: such words express only the depth of their pain and not their true thoughts. Then comes sadness, which can be very deep - even a true depression. Then after all these phases: acceptance. The parents are able to think clearly, to imagine the future, to organise themselves. It is as if they are alive again after going through a very dark passage.

It is very important to explain to the parents, listening to them separately and addressing them one to one, that they will go through all this, but they will do it in their own way, so that they will very often not be at the same stage and will react differently from the other parent. It is important to tell the parents this, since if their reactions are too different, this may cause extra pain. Parents may imagine that the person they are married to is different from what they thought and that they made a mistake in marrying him or her. I remember a couple who were expecting a baby and the diagnosis was Trisomy 21, Down's Syndrome, and the father came to the stage of acceptance very, very quickly. After a few hours he was organising the return of the couple to the family and how they would tell their children. The mother remained in a state of denial for a very long time and spoke very, very strong words about the baby. The father was horrified to hear his wife speaking of a 'monster' and using very harsh words and he was deeply hurt by that. Very luckily someone explained to him that this was normal. The wife later came to acceptance, and the baby was deeply loved by both. I think that this difference in emotion is very common and can cause very deep hurt for the couple. It is difficult to have a disabled child, but the couple needs to be taken care of too. It is important to explain to the family that violent and aggressive words are an expression of pain and do not reflect the couple's real thoughts.

At this stage the physician must take care to avoid causing extra suffering. If a doctor pushes a couple into a very quick decision to have an abortion, this will happen at precisely the moment when the couple is paralysed, at the first stage, or in a state of revolt and anger: two very bad conditions in which to make an important decision and a free one. The conditions of free choice are not being met.

It is very important also to give the parents time, because they have to form their own judgement about the decision: considering different points of view, considering who the baby

is. They have to think of the baby not only from a medical point of view, as we are not just a body - something that doctors often forget.

The doctor has to explain the medical part of the situation, but he must help the parents to also consider the other aspects of their baby: there is, in the case of each human person, a medical aspect, but also a mental aspect, affecting the family - a philosophical and spiritual aspect. They have to consider all these aspects of their baby and of the situation they are in and view the decision from a philosophical and spiritual point of view, a family point of view, and not only from a medical point of view: 'can we cure, or can we not cure?' The doctor may give a medical opinion, but the parents should ask their close friends, and their own parents, for their opinion. They can speak to other parents who have gone through the same situation. Most of all they should speak with a priest: one they know if possible, perhaps the priest who prepared them for their marriage. I always think if they are lucky enough to know him a bit and if they can contact him, he really is the best person to help.

So they will try to consider the situation from this different point of view, trying to come together, to come to a good decision for them and for the baby. In contrast to the frame of mind which may lead them to choose abortion, parents are generally very peaceful when they realise that the baby is not suffering, and will not suffer after birth, but will live out his entire natural life, even if this life is dramatically short, and that he will die naturally. Although the parents' pain is of course severe during these months, they are increasingly at peace. It is surprisingly little known that peace and deep pain can exist together - especially now when, in our society marked by consumerism, we cannot imagine that something that is not pleasant can bring happiness and peace in a deep sense. But I do not say that it is a happy thing to wait for the birth of a disabled child. I think that it is a very cruel experience, but although cruel, it can be peaceful too.

Of course all this information cannot be given in one appointment, so the doctor will have to see the couple several times. Generally when you see these parents, you just take your watch off. I used to do this. I took the clock off the wall, so I did not look at it and say 'oh I have something else to do', because I thought that all my time had to be given to this couple. The couple must know that they will not be alone during the following months, facing the decision, because sometimes it does take several months. I always give my personal mobile number to the couple, asking them to use it as often as they want or need to. I discovered - and this is not surprising - that when I decided to give my telephone number almost no-one rang me, because they knew they could do it and that changed everything. So give your number - it is not so dangerous.

After the decision has been taken by the couple to continue with the pregnancy, it is necessary to remain very close, ready to answer any questions and give support if sorrow or worry becomes too strong. The clinical work goes on with the mother: the examinations, extra and special examinations of the pregnancy. The baby is checked too and the ultrasound scan is sometimes the moment when the parents can meet the baby more clearly. I remember very well a mother who was expecting a baby who was terribly deformed, so the ultrasound was very difficult and we thought, perhaps it would be better that she not look at the baby, but she said, 'it's a meeting for me, so I am very happy because now I know my baby better.' Of course we do as the parents wish.

It is important to help the couple to decide what they will say and to whom they will speak about the baby; in particular, when speaking to other children they may have. Generally the best thing is to say that they are worried because the baby is ill, and that the doctors are not sure if they will be able to cure him. It's better not to go into details with the children. Saying this explains to the children why the parents look sad and for the children it is essential to hear the reason for a problem, as they will always feel it, even if the parents try to mask it, because if they know that there is a problem, but the problem is not explained this makes the children very anxious. We are very clever parents, but we cannot heal our children. Whether we tell our own parents may depend on their age, but generally it is best to be open. The same applies to brothers and sisters. Sometimes when the couple rely on their own parents to be supportive, because they have always given them strong values, they discover very painfully that the parents try to push them to make a decision they do not wish to make. So sometimes parents are not helpful, but this is rare.

Friends: I recommend choosing a few good friends to tell, so that the couple can talk to them if they wish, because they need to have someone to talk to when the sorrow is too heavy and generally the couple do not want to be too sad with their own parents or with their husband or wife. So they feel in a kind of prison, being able to speak to no-one: it is important to be able to say 'it is hard'. They can talk to the doctor too.

The parish: it is important that the parish community prays for its members and the best thing is to tell someone you know and ask for anonymous prayers from the community. Sometimes you hear that religious congregations or people you never have heard of and who you will never know, have prayed for you, and you perceive the communion of saints.

Maybe this will sound astonishing, but I always advise my patients, when they are Catholic, to write to the Holy Father (the Pope), and they always say 'oh it is impossible; we would never dare to do this.' I always encourage them very strongly and each time they do, the Holy Father has answered with very nice words and a special blessing. I think that has helped the couples, but my idea was that these parents had to give our Holy Father a testimony that some parents practice what they have heard. I think that these parents give the Holy Father joy and I tell them 'not many parents can say they have given joy to the Holy Father, so please go ahead.'

Less frequently it is necessary to inform the teacher(s) of the older children, so that he can help and support the children, and understand why they are not happy.

It is very difficult, but necessary during the pregnancy to meet with the paediatric team who will be in charge of the baby after the birth, so that the parents are reassured that everything is well prepared, and to avoid a stressful and unusual situation for the medical team. It is difficult for the paediatrician to face such a situation - well, it was difficult, I hope in the future I will not have to say this, as everyone will be used to it - well, let's hope.

It is necessary to check whether the paediatric team has experience of such a situation and that they are prepared and that procedures will be written in the medical documents, so that everything is organised. Sometimes it may be necessary for the couple to change the hospital where the baby will be delivered, if the obstetric or paediatric team are too disturbed by the situation, or refuse to face it, which happens sometimes.

It is time too, for the parents to choose godparents, if a baptism is wished.

The moment of delivery and birth is always a moment full of emotion for everybody: the couple, the family and the medical team too. A natural delivery is of course always preferred, and this happens as naturally as possible. The medical teams I have seen have always been devoted to the couple. This support is very important. The parents meet their child, which is humanising: the child is dressed and if abnormalities can be seen, the team leader takes care of dressing the baby in a little cap or a nice dress, so that the baby looks as normal as possible.

The baby is given to the mother and to the father, when the abnormalities are not too severe, and then afterwards, washed and dressed. That is very important: for the three of them to meet and be alone for a few minutes, so that they can get to know each other and the parents can enjoy their baby and moreover, so that they realise it's a beautiful baby, not at all like the terrible ideas they will always have had during the preceding months. The paediatricians will just check periodically that the baby is not in pain, and if he is, a pain relieving injection will be given.

The short life of the baby must be peaceful and without suffering, as has previously been promised to the parents. It is time for the baptism and confirmation, and it is best to have chosen in advance who will baptise the baby. A priest known to the couple, if he can get to the hospital quickly - sometimes he even arrives before the birth - or a resident priest or nun if the hospital is lucky enough to have one. The godparents, grandparents or any member of the medical team. At this time it is very important to take photographs of the baby and of the baby in the arms of his parents. These will also provide mementos for the family history and will allow the baby to have a real existence in the family.

After a varying amount of time the baby will be unable to live any longer and generally it is in a peaceful atmosphere that he dies, helped by drugs if necessary to avoid suffering, but respecting the natural moment of his death. He will be made comfortable and his needs respected. Sometimes after the baby dies the parents ask to present him to their family and to the other children and they want a celebration to take place to say goodbye.

All this requires a great deal of time and dedication on the part of the medical team, which is why it is often preferable to organise the birth in a place where the team is experienced in these situations.

I have often heard of friends who were very reluctant to come to the burial of such a baby, because they were terrified, but afterwards, they say, 'oh I am not afraid of death now as much as I used to be', and so I think it is a witness and an act of very great trust on the parents' part towards all their friends, who have followed the pregnancy, and can see that this decision is peaceful and that there is hope.

I also encourage the parents to send a note to their family and friends as they would have done for an ordinary baby, announcing at once the baby's birth, baptism, and death. It seems a very small detail, but it helps the parents to give the baby his proper place in this way, because this document will always remind them and be in the family scrapbook, and it gives them comfort that everybody knows what has happened. It helps to avoid embarrassing situations and painful explanations, each time the parents meet someone who doesn't know what has happened. This situation is painful for the parents and also for the friends they meet, who with a big smile say 'and how is the baby?' and oops, everybody starts to cry. It helps others too to be prepared to act peacefully and intelligently when they

face the parents, which is sometimes difficult. A message on the anniversary will be welcomed by the parents too, because this shows that the baby is still remembered.

And God: although I have been technical in my presentation, you may have felt that God is everywhere too. First, the doctor and the whole medical team have to ask Him to help us in the giving the diagnosis and to support us - to support the couple, of course, but to support us too, through this diagnosis and through all these things we have to do and that will happen afterwards. Then when the parents have faith, in any religion, it's a precious support to help them at the terrible moment of the diagnosis, and then to go on and to pass through anger, and fear, to peace and acceptance, allowing their lives to be rebuilt. Again I say, it doesn't make the sorrow less: the sorrow is always there.

What to say about God's love and presence? Very simple words are best, always saying how much the couple are loved, as is their baby and that it is not God who sent this suffering, but that He came to share it with us and take on some part of their pain. We must help the parents to realise that their anger, their fear, their sadness or lack of hope are nothing to be ashamed of. Even Jesus on Holy Thursday was full of fear in thinking of the pain to come. Even He asked his Father to save him from it, and even He at the moment of His death asked God 'why did you abandon me?' So the parents can be reassured if they feel fear, despair or lack of hope - if they doubt God's existence, His infinite charity and love - that Christ shared these violent thoughts with us: he shared all of our humanity. If He felt like this, we do not have to be ashamed of it. This will give great comfort to the parents, who are often ashamed not to be stronger.

The Virgin Mary with her fiat to a very unusual and difficult situation can share with parents this confidence, so as to support them in their very hearts.

The parents and the baby are in some way Christ for the doctor. 'Whatever you do to the least of my flock, you did it to me' - so our attitude to the parents and the baby must be professional and full of love. But we must be a reflection of Christ for the patients and for the baby. They expect us to behave as Christ and they trust us to try to. This is one of the honours of our profession. Serve others as if they were Christ; try modestly be a reflection of Christ's love for all those who come to us. Of course we know that we are so imperfect, so bad, so cruel; we do our best and we ask God to make all well. He always answers, although not always in the way we have imagined.

To finish, I would just like to quote a few words one mother wrote to me. She was expecting her first baby. In the third month of her pregnancy a severe abnormality of the brain was discovered and we were sure that it would cause the death of the baby a few hours after delivery. She was living in Spain, because her husband was working there and I was in contact with the medical team, who were very disorganised and did not expect to have to face this situation. She sent me this email. They called their daughter Marie Lys. Lys means lily - the flower of the Holy Virgin.

'She was born last Friday at 7:45 in the morning and left us at 18:15 in the afternoon, in peace. The delivery went very well. She was breathing on her own and her heartbeat was normal. They put her body on my tummy before the paediatricians took her. She received no treatment, only monitoring for her heart. We have been very well supported by a competent medical team. At the end of the afternoon, it became too difficult to breathe, so she stopped and then her heart as well. She has lived her entire life, although it was very

short, and went without suffering, in peace. Thank you for accompanying us through all this time.'

So I hope that the testimony of this family, and I have seen many families, who went through this very difficult challenge, shows they have received great peace and have been very relieved that their baby was seen as a true person, a true human being and that the dignity of their child was completely recognised and so the dignity of the parents too. And I think the whole experience was better and easier to go through. It's just a very modest testimony, what I try to do, but I am very happy that now many parents can be accompanied in this way. A family wrote a book about this adventure. Not one of my families, but in another city in France: I was very surprised that there was a lot of talk about this book and that many teams realised that this was a good way to act. So since that time they go on managing these pregnancies in a good way. Thank you very much.