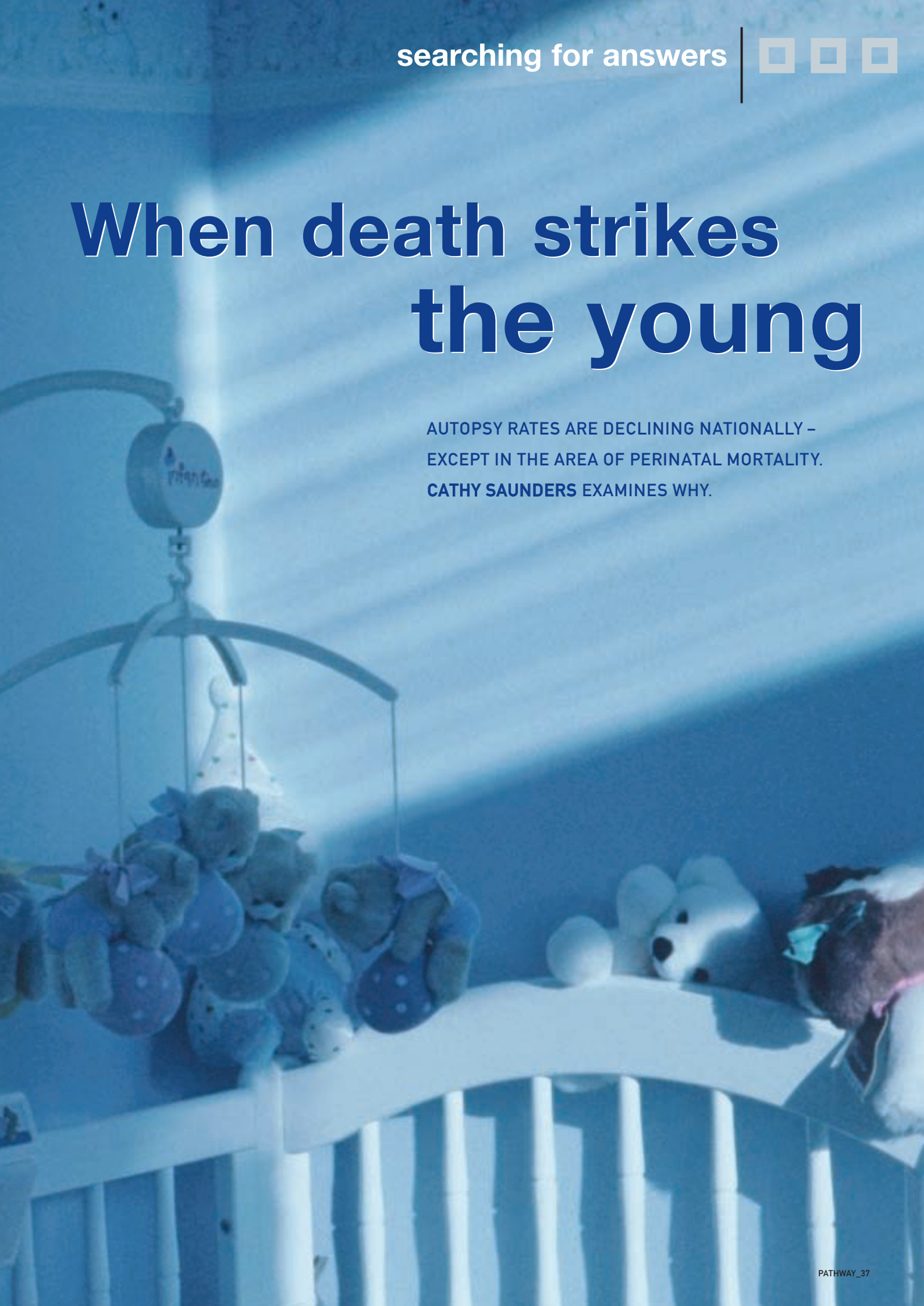
When death strikes the young

AUTOPSY RATES ARE DECLINING NATIONALLY – EXCEPT IN THE AREA OF PERINATAL MORTALITY. **CATHY SAUNDERS** EXAMINES WHY.



"The public perception that the autopsy is an intrusion after death needs to be replaced by one that emphasises that it is an investigative and diagnostic procedure" – Professor Yee Khong

When parents lose a baby before or soon after birth, often their first question is "Why?".

In many cases, an autopsy can provide the answer but also, most importantly, help with the management of future pregnancies.

Perinatal pathology is integral to unlocking this information, and involves the synthesis of post-mortem tests that may include anatomical pathology, microbiology, virology, immunology, biochemistry, haematology, chemical pathology, molecular biology and genetics.

"We put it all together and find the most likely reason for the baby dying," says Professor Jane Dahlstrom, Professor of Pathology at the Australian National University and senior Anatomical Pathologist at ACT Pathology and The Canberra Hospital.

Getting answers and using them to move forward is fundamental to many parents' sensitive decision to have an autopsy in an era when adult autopsy rates are declining.

Perinatal autopsy experts say only a handful of parents regret having agreed to an autopsy, while many rue the fact they did not consent to one.

"The overall rate of perinatal mortality in Australia now is less than 1% of all births, so it is a relatively unusual complication of pregnancy and I think we are satisfying a natural need to know why it happened," says Professor David Ellwood, Professor of Obstetrics and Gynaecology at the Australian National University and Director of the Fetal Medicine Unit at The Canberra Hospital.

"It does give people some degree of closure. I think it is different from adult autopsy, where quite often the death is expected and so perhaps there isn't the same level of uncertainty."

Australian research shows that the rate of adult autopsies decreased from 66% of all autopsies in 1992–93 to 39% in 2002–03, while the rate of perinatal autopsies climbed from 29% to 58% of all autopsies in the same period (MJA 2004;180:281–5).

Perinatal autopsy rates are now 60–70%, compared with about 5% for non-coronial hospital adult autopsy rates.

A many-valued thing

Professor Dahlstrom says the value of an autopsy, which means "to look within with one's own eyes," is manifold.

The primary aim is to establish the cause of death, but it also serves to confirm – or, in up to 20% of cases, refute – the clinical diagnosis.

In addition, the autopsy can reassure parents they did not do anything during the pregnancy to jeopardise the baby's wellbeing, and it eliminates suspicion of inappropriate or inadequate treatment.

Dr Diane Payton, Chair of the RCPA Paediatric Pathology Advisory Committee and senior staff pathologist at Royal Brisbane and Women's Hospital, says there are also medico-legal benefits.

"If there has been a problem with the pregnancy, delivery or early perinatal course or any unexpected outcome, a full post-mortem examination and an open discussion of the post-mortem results, clinical course and all other investigations is very helpful in discussions with the parents," she says.

Studies confirm that a perinatal autopsy provides useful information in a large number of cases. Research by Professors Dahlstrom and Ellwood and Canberra neonatal specialist Dr Alison Kent into perinatal deaths[1] shows that in the ACT and NSW over a five-year period to 2005, an autopsy was carried out in 50% of perinatal deaths and placental pathology in 95% of such deaths.

In about 40% of these examinations, additional information was provided that prompted further investigations postnatally and/or changed management of the next pregnancy.

Similarly, research in WA[2] shows that in half of perinatal autopsies in 2000–01, the findings made a difference, either by changing the diagnosis or adding extra information.

Professor Ellwood says it is important that both an autopsy and placental pathology are done.

"If families are resistant to having a post-mortem, then as a minimum the placenta should be looked at."

Professor Dahlstrom agrees.

"About one-third of the time, the answer to why a baby has died is in the placenta and the baby can be perfectly normal," she explains.

Causes include extensive placental infarctions and villitis.

Another one-third of deaths are caused by major congenital abnormalities in a baby and the remaining third may be related to maternal conditions such as systemic lupus erythematosis, diabetes or severe hypertension.

Guiding future care

By providing answers to the cause of death, an autopsy paves the way for future pregnancies to be managed differently.

"Women who have experienced stillbirth have a higher rate of stillbirth in subsequent pregnancies," says Professor Ellwood.

"So, for example, if the problem was to do with fetal growth or placental function, you may well monitor the growth of the fetus much more closely and perhaps think about early delivery."

Autopsies can also detect the placental features of thrombophilias, which can be treated, and this may improve the outcome of the next pregnancy.

They can also identify genetic abnormalities, which may have a recurrence risk in subsequent pregnancies and might also affect the future pregnancies of siblings. The information from autopsies can be very important in genetic counselling and may have implications for prenatal testing.

Dr Adrian Charles, of the Department of Perinatal Pathology at Perth's King

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Edward Memorial Hospital for Women, says perinatal autopsies have sometimes led to changes in clinical practice.

In the UK, autopsies on several neonates who died suddenly showed the cause was cardiac tamponade or fluid around the heart. Further investigations revealed they had all had a long-line catheter inserted into their right atrium, which had led to fluid leaking. This surrounded and compromised the heart.

Opening up options

"This finding materially altered practice," Dr Charles says.

Despite best efforts, some deaths remain unexplained, but parents are often relieved to learn from the investigations that events during the pregnancy that may have worried them were unlikely to have been of any significance.

When an autopsy is performed, the incisions are minimal and the parents can

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Moving forward

When Karina Christensen and her partner Grant (pictured) lost their first baby Ryan 26 hours after he was born three years ago, they did not hesitate to agree to an autopsy.

Although two of Karina's siblings had died shortly after birth from a genetic disease – autosomal recessive polycystic kidney disease – she always believed it would not affect her children because it requires both parents to be carriers.

"I thought it could not be possible my husband would be a carrier, that it was not going to happen to us," she says.

But the 20-week ultrasound showed Ryan was affected. Karina says they proceeded with the pregnancy in the hope that somehow he might pull through.

"After he died, we wanted to confirm what it was and in doing that, we could then go forward," she explains.

Although her parents had been told the cause of her siblings' deaths, no autopsies had been done or blood tests taken, so Karina and Grant found the autopsy removed any doubts. "It gave us closure to know exactly what happened," she says.

The information from the autopsy also enabled them to make decisions about their next pregnancy. As there is a one in four chance of having an affected baby, they underwent IVF and had prenatal genetic testing to ensure the implanted embryo was unaffected.

The couple now have a beautiful three-month-old boy, Daniel, and are already planning their next baby.

Karina says they are extremely grateful to Dr Alison Kent, neonatal specialist at The Canberra Hospital, who came to see them at the 24-week ultrasound of Ryan and prepared them for their options once he was born.

"Alison and her staff were absolutely amazing and pulled out every stop to help us," Karina says.

She also sings the praises of the perinatal pathologist, haematologist and geneticist who were involved in the autopsy. To show their gratitude to The Canberra Hospital, she and Grant regularly donate items for the baby packs given to new parents.

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HOPE after heartbreak

In 1998, Professor Dahlstrom (pictured) examined a baby who had died in utero and decided to check the findings from an autopsy conducted by another pathologist on a previous fetal death in the same mother. She diagnosed neonatal haemochromatosis which, at the time, was not treatable.

More recently, when treatment for the condition finally became available, Professor Ellwood and immunopathologist Professor Paul Gatenby instigated this treatment during the pregnancy of the same woman, who by now had had five stillbirths.

"She delivered a perfect baby at the end of last year," Professor Dahlstrom says.

"The doctors sent me a note saying 'Well mother and baby, beautiful placenta'. I went to see the mother. She was very happy to see me."

Such results make autopsies very worthwhile.

"If we had not done an autopsy, we would never have known what was causing the pregnancy losses."

hold and even, in some cases, bathe the baby afterwards.

If parents do not want a full autopsy, an option is a limited autopsy. For example, if an ultrasound during pregnancy detected abnormalities in the heart or kidneys, the parents might consent to those organs being examined.

An even more acceptable choice to some parents who refuse an autopsy are simple, non-invasive investigations such an external examination and photos, x-ray and ultrasound of the fetus.

There is also another initiative that has made autopsies more acceptable to many parents.

By law, the death of any fetus beyond 20 weeks' gestation or with a birthweight greater than or equal to 400gms is deemed a perinatal death and the birth and death must be registered and a burial or cremation performed.

There was a time when a fetus below that gestational age was disposed of with

other surgical specimens, but things have changed.

Dr Susan Arbuckle, head of Histopathology and Chair of Diagnostic Services at The Children's Hospital at Westmead in NSW, says after a lot of effort, she was successful in getting a crematorium to agree two years ago to cremate groups of fetuses. "I had to obtain rulings on the law and permission for the cremation of a group of fetuses together as the law states you can only cremate one person at a time," she says.

She then had to find a crematorium – which ended up being a private crematorium - that was happy to comply.

"A number of other hospitals in the last couple of years have now followed suit using my letters and principles, which is satisfying," she says.

Now, many hospitals in most states offer parents a private burial or cremation, or a hospital mass cremation after which the ashes are scattered in a remembrance garden during a service for their baby. Many hospitals also hold memorial services in their chapel once or twice a year for these parents.

But Dr Arbuckle says the autopsy service in NSW is up against a lack of funding from the state government to enable all autopsies to be done by expert perinatal pathologists.

"It would take some money – always an issue – and willingness on their part to actually put in place places of expertise and support with structure and transport systems," she says.

Hurdles remain

There are other barriers to perinatal autopsy in Australia. Parents may refuse an autopsy if there are cultural and religious taboos, while others may be deterred by clinicians who don't talk positively about autopsies or if the delicate matter is left to inexperienced junior doctors.

Some clinicians fear if the autopsy turns up something, parents may sue.

In rural Australia, the need to transport the body long distances to the nearest major city can deter parents who do not want separation from their baby.

Professor Yee Khong, the RCPA South Australian state councillor and paediatric anatomical pathologist at the Women's and Children's Hospital in Adelaide, says public confidence rightly took a knocking following the 'organ retention' controversy in the UK in 2000, when several hospitals were exposed as having retained children's organs and body parts following post-mortem examinations, mostly without the knowledge of the families of the deceased children.

"However, the root cause of the problem has been the lack of public information about the benefits of the autopsy and of the process itself," he says.

"The public perception that the autopsy is an intrusion after death needs to be replaced by one that emphasises that it is an investigative and diagnostic procedure."

Professor Khong says another barrier is the fact that, following the organ retention crisis, some consent forms are now so cumbersome that clinicians may take the easy route by not seeking consent, so autopsies cannot be performed.

Workforce pressure

Workforce issues are also a factor, he adds. Diagnostic workloads in anatomical pathology have increased without a commensurate increase in pathologists, so surgical pathology and cytology are often prioritised over the autopsy.

Experts agree that the perinatal autopsy rates should be higher. In the UK, the Royal College of Obstetricians and Gynaecologists and the Royal College of Pathologists recommend a minimum rate of 75%, and here in Australia rates of more than 90% were achieved in the late 1980s and early 1990s.

Most states are making concerted efforts to increase their perinatal autopsy rates, and most hospitals have special teams who provide counselling support to parents who lose their babies, and clinico-pathology meetings to provide feedback to the clinicians and nurses.

Professor Ellwood runs a perinatal loss clinic at The Canberra Hospital where he sees women in the ACT and surrounding areas of NSW who have lost babies.

At the King Edward Memorial Hospital for Women, a midwife coordinates a perinatal loss clinic where, once a fortnight, a paediatric perinatal pathologist, fetal medicine specialist, neonatologist, paediatrician, chaplain, midwife, social worker and psychologist

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are available to talk to the parents. The clinic is open to parents throughout the state and occasionally a telemedicine conference is held for families in the country.

Also, the hospital's perinatal pathology department routinely takes photos and hand and foot prints of stillborn babies as a memento to hand to parents.

In Queensland, pathologists are trying to get more colleagues with expertise in perinatal autopsies to help reduce the turnaround time.

In Victoria, the head of Pathology at the University of Melbourne, Professor Paul Monagle, says hospitals are working with parent support groups to increase community understanding, while a study at the Royal Women's Hospital is also underway to discover parental views on perinatal autopsy.

"The aim is not to increase the numbers per se, but to ensure an appropriate service is offered to all families who suffer perinatal loss," Professor Monagle says.

In most states, pathologists talk to clinicians, junior doctors, GPs training in obstetrics, nurses and midwives about the benefits of an autopsy.

"I think the most important thing is to make sure the staff are all singing from the same song book and that the counselling for autopsy begins as soon as possible," Professor Ellwood says.

"In some cases, it may actually be before the baby dies if you think that is inevitable."

References

1. ***Poster presentation, Perinatal Society of Australia and New Zealand, 11th annual congress in Melbourne in April 2007***
2. ***11th Report of the Perinatal & Infant Mortality Committee of Western Australia 2000-01 (WA Department of Health)***