

Siblings of infants who have died suddenly and unexpectedly at 10-fold risk of same death

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The siblings of infants who have died suddenly and unexpectedly run 10 times the risk of dying in the same way, indicates a long term analysis of



monitoring data, published online in the *Archives of Disease in Childhood*.

Such deaths remain rare, but affected parents need extra help to cut the risks of recurrence, say the researchers.

Each year in England and Wales, up to 400 <u>infants</u> die suddenly and unexpectedly, an occurrence referred to as a <u>sudden unexpected death</u> in infancy, or SUDI for short. Many of these deaths can't be explained.

To allay parental anxieties about another child dying in this way and minimise the risks, The Care of Next Infant (CONI) programme was set up in 1988 for families in England, Wales and Northern Ireland, as well as those in the Crown dependencies (Jersey, Guernsey and the Isle of Man), and the British Armed Forces overseas.

The programme includes regular home visits from a health visitor until the child is at least 6 months old, and the provision of breathing monitors, basic life support training, symptom diaries and weight charts.

To find out how many families experience a repeat SUDI, and why, the researchers drew on details of the infants registered with the UK CONI programme between 2000 and 2015 inclusive.

In all, 6608 live born infants were registered in CONI during this period, 171 of whom were first-borns to mothers whose male partners had previously experienced a SUDI.

Repeat SUDIs were rare, with only 29 such deaths reported in 26 families between 2000 and 2015. There were two SUDIs in 23 of the families, and three in the other three.

This equals a SUDI rate for infants born in families with one previous



SUDI of nearly 4 per 1000 <u>live births</u>, which is more than 10 times the UK rate of unexplained infant deaths of 0.31 per 1000 live births in 2016, and more than nine times higher than the rate of 0.43/1000 in 2006.

And the SUDI rate of a third death in a family with two previous SUDIs was 115 per 1000 births (3 among 26 families over the entire period).

The explanations for the deaths of the first SUDI were sudden infant death syndrome (SIDS) in 11 cases; unascertained in 8 cases; medical in 3; accidental suffocation in 2; and murder/probable murder in 2.

The causes of deaths among the SUDI siblings were SIDS in 10 cases; unascertained in 5; medical in 4; accidental suffocation in 6; and murder/probable murder in 4.

Modifiable risk factors for SUDI include a mother who smokes before and after the birth; a mother with mental health issues; unsafe sleeping such as sharing a bed/sofa with a parent who has used illegal drugs or drunk more than 2 units of alcohol; and child abuse/neglect.

Among the SUDI siblings, 24 of the mothers smoked; unsafe sleeping occurred in 11 cases; 13 of the mothers had <u>mental health issues</u> before or after the birth; parenting concerns in 17 cases; and abuse or neglect in 10.

These factors may or may not have contributed to the repeat SUDI, but they do highlight how vulnerable the families registered in CONI are, point out the researchers.

Although this is the most complete set of data on sibling SUDIs available in the UK, the CONI programme is nevertheless voluntary, so the figures may be an underestimate, caution the researchers. Nor were they able to



gather information on potentially influential risk factors for SUDI, such as low birthweight or premature birth.

Nevertheless, they conclude: "The risk of a repeat SUDI in a <u>family</u> is 10 times that of the general population, reflecting both inherent genetic risks as well as environmental factors such as maternal smoking and unsafe sleeping.

"CONI cannot address intrinsic risk factors, but these are very vulnerable families who need comprehensive care and support packages to help them understand safe sleeping, address mental health problems, and enhance their parenting capacity."

More information: Recurrent sudden unexpected death in infancy: a case series of sibling deaths, *Archives of Disease in Childhood* (2020). DOI: 10.1136/archdischild-2019-318379

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