

**Submission on: Effective mental health care in the perinatal period: Australian clinical practice guideline  
- 2022 consultation draft**



**Name: Pieta Shakes – Executive Director**

**Organisation: Through the Unexpected**

[www.throughtheunexpected.org.au](http://www.throughtheunexpected.org.au)

[info@throughtheunexpected.org.au](mailto:info@throughtheunexpected.org.au)

**Please provide comments under the relevant heading(s)**

**General comments**

*Through the Unexpected*<sup>1</sup> is a health promotion charity founded to improve the psychosocial outcomes of parents who receive the news that their unborn baby has a difference in their health, development or genetics. We are the only organisation in Australia that exists with the specific focus on improving psychosocial outcomes for parents who receive any type of prenatal diagnosis and walk any path through the unexpected. As a volunteer led charity, we do not yet have the capacity or funding to provide direct parent services, unlike the UK government-funded service, Antenatal Results and Choices<sup>2</sup>. Instead, our activities function to develop resources and build the capacity of existing organisations and health and allied health professionals to provide trauma-informed, parent-centred care to parents who receive a prenatal diagnosis. We also advocate for recognising and reducing the striking gaps in psychosocial support for parents who receive a prenatal diagnosis of a fetal anomaly or variation.

We are pleased to see the update of the Mental Health Care in the Perinatal Period Australia Clinical Practice Guideline, herein the Guideline, and for the opportunity to provide feedback. We specifically noted the comment about the intent to include the review of evidence relating to the impact of a fetal/neonate congenital anomaly diagnosis and were disappointed to see that funding could not be secured for this. We thank Dr Nicole Highett and the team at COPE for advocating for the inclusion of prenatal diagnosis. As the lack of funding reflects the high-level issue related to the overlooked nature of the experience and psychosocial aspects of prenatal diagnosis, we directed energy towards building a community response to the recent Senate *Inquiry into universal access to reproductive healthcare*. We are delighted to share that many organisations and individuals sent submissions to raise awareness of the striking gaps in psychosocial care after a suspected or confirmed prenatal diagnosis and of the acute and enduring impact on families. We hope to continue this advocacy to ensure there is funding for the following Guideline review in five years. We offer our support to establish that funding and to participate in any way.

<sup>1</sup> [www.throughtheunexpected.org.au](http://www.throughtheunexpected.org.au)

<sup>2</sup> <https://www.arc-uk.org/>

We have a team of researchers currently undertaking an evidence synthesis of psychosocial outcomes of women who receive a prenatal diagnosis, following the Cochrane rapid review methodology, with a specific focus on outcome studies that engaged measurement tools. We hoped this review would be completed within the submission timeline. Unfortunately, the review has taken longer than anticipated, largely due to the amount of included studies (n=67) and partially due to re-directed efforts to raise community awareness of the Senate inquiry. Instead, we can provide a snapshot of the evidence of the under-acknowledged, unmet psychosocial needs of parents who receive a prenatal diagnosis:

- 88% of mothers and 83% of fathers experienced prenatal diagnosis as a traumatic event.<sup>3</sup>
- Suicidal ideation was significantly more prevalent in mothers who received a prenatal diagnosis than mothers with a typically-developing baby.<sup>4</sup>
- 39% of mothers who continued their pregnancies met full diagnostic criteria for PTSD,<sup>5</sup> and 85% experienced ongoing symptoms.<sup>6</sup>
- Anxiety after a prenatal diagnosis was rated as moderate to severe in 1 in 2 women.<sup>7</sup>
- In one study, at 6 weeks and 6 months postpartum, parents who received a prenatal diagnosis reported significantly increased psychological distress compared to parents who received a postnatal diagnosis.<sup>8</sup> Other studies suggest the psychosocial outcomes of parents who receive a prenatal or postnatal diagnosis are similar.<sup>9,10</sup> One study suggested increased anxiety for mothers given a postnatal diagnosis, although authors referred to the *Trait* anxiety score, rather than *State* anxiety, which showed no differences. Together, these findings conflict one of the overarching aims of antenatal screening – to provide parents with the opportunity to prepare for the birth of their baby with a high likelihood of morbidity,

---

<sup>3</sup> Aite, L. et al. (2011). Antenatal diagnosis of congenital anomaly: a really traumatic experience? *Journal of Perinatology*, 31(12), 760-763

<sup>4</sup> Kaasen, A. et al. (2017). Maternal psychological responses during pregnancy after ultrasonographic detection of structural fetal anomalies: A prospective longitudinal observational study. *PLoS One*, 12(3), e0174412. <https://doi.org/10.1371/journal.pone.0174412>

<sup>5</sup> Rychik, J. et al. (2013). Maternal psychological stress after prenatal diagnosis of congenital heart disease. *Journal of Pediatrics*, 162(2), 302-307 e301. <https://doi.org/10.1016/j.jpeds.2012.07.023>

<sup>6</sup> Horsch, A. et al. (2013). Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly. *Prenatal Diagnosis*, 33(12), 1137-1145. <https://doi.org/10.1002/pd.4207>

<sup>7</sup> Fontoura, F. C. et al. (2018). Anxiety of mothers of newborns with congenital malformations in the pre- and postnatal periods. *Revista Latino-Americana De Enfermagem*, 26, e3080-e3080. <https://doi.org/10.1590%2F1518-8345.2482.3080>

<sup>8</sup> Skari, H. et al. (2006). Prenatal diagnosis of congenital malformations and parental psychological distress—a prospective longitudinal cohort study. *Prenatal Diagnosis*, 26(11), 1001-1009

<sup>9</sup> Werner, O., El Louali, F., Fouilloux, V., Amedro, P. & Ovaert, C. (2019). Parental anxiety before invasive cardiac procedure in children with congenital heart disease: Contributing factors and consequences. *Congenital Heart Disease*, 14(5), 778-784. <https://doi.org/10.1111/chd.12777>

<sup>10</sup> Bevilacqua, F., Palatta, S., Mirante, N., Cuttini, M., Seganti, G., Dotta, A., & Piersigilli, F. (2013). Birth of a child with congenital heart disease: emotional reactions of mothers and fathers according to time of diagnosis. *The Journal of Maternal-Fetal & Neonatal Medicine*, 26(12), 1249–1253. <https://doi.org/10.3109/14767058.2013.776536>

mortality or disability. As such, we are failing to provide parents with the support they need to adapt and prepare, and in some cases, parents are being harmed through judgment and stigma<sup>11</sup>, poorly coordinated services or a lack of trauma-informed practice.

- A 'high chance' screening result impacts long-term mental health even when the baby does not have an anomaly.<sup>12</sup>
- An Australian-based study about the experience of decision-making after a prenatal diagnosis found that many of the 102 parents interviewed felt unsupported immediately after receiving the unexpected news.<sup>13</sup>
- Anxiety, depression and PTSD symptoms are frequent in the early stages of a pregnancy following a termination for medical reasons (TFMR).<sup>14</sup>

With acknowledgement of the lack of funding impeding the Expert Working Group from undertaking a full review of literature related to prenatal diagnosis within this 2023 update of the Guideline, we call for the inclusion of prenatal diagnosis within the narrative parts of the Guideline. While there are specific guidelines and recommendations for the delivery of prenatal screening, the psychosocial consequences for parents who receive unexpected news are grossly overlooked. This lack of attention of the psychosocial impacts is also reflected by the:

- single recommendation in the national Clinical Practice Guidelines: Pregnancy Care<sup>15</sup> to refer women to trained professionals for counselling and ongoing support. This recommendation fails to provide specificity about psychosocial support, as prenatal counselling is information giving about the diagnosis and expected prognosis<sup>16</sup> rather than therapeutic counselling. Furthermore, the guidelines recommend a service and booklet that is no longer available.
- lack of consideration of the psychosocial impacts in the economic analyses related to antenatal screening.<sup>17</sup>
- initial draft of the Stillbirth Clinical Care Standards did not include fetal anomalies in the tabled risks of stillbirth or recommend support for parents who receive a prenatal diagnosis of a life-limiting anomaly. We are pleased to report the final Standard did include prenatal diagnosis and

<sup>11</sup> Down Syndrome Australia. (2020). "We have a lot to learn." Prenatal screening for Down syndrome: A discussion paper. [https://www.downsyndrome.org.au/wp-content/uploads/2021/10/DSA\\_Prenatal-Screening-Experiences.pdf](https://www.downsyndrome.org.au/wp-content/uploads/2021/10/DSA_Prenatal-Screening-Experiences.pdf)

<sup>12</sup> Kristjansdottir, H., & Gottfredsdottir, H. (2014). Making sense of the situation: women's reflection of positive fetal screening 11-21 months after giving birth. *Midwifery*, 30(6), 643-649. <https://doi.org/10.1016/j.midw.2013.10.024>

<sup>13</sup> Hodgson J. et al. (2016). Experiences of prenatal diagnosis and decision-making about termination of pregnancy A qualitative study. *Australian and New Zealand Journal of Obstetrics and Gynaecology*. <https://doi.org/10.1111/ajo.12501>

<sup>14</sup> Beauquier-Maccotta, B. et al. (2022). Prenatal attachment, anxiety and grief during subsequent pregnancy after medical termination of pregnancy. Attachment to which child? *Journal of Gynecology Obstetrics and Human Reproduction*, 51, 102353. <https://doi.org/10.1016/j.jogoh.2022.102353>

<sup>15</sup> Australian Government Department of Health. (2020). Clinical practice guidelines: Pregnancy Care.

<sup>16</sup> Kratovil, A.L. & Julion, W.A. (2017). Health-care provider communication with expectant parents during a prenatal diagnosis: an integrative review. *Journal of Perinatology*, 37, 2-12. <https://doi.org/10.1038/jp.2016.123>

<sup>17</sup> Australian Government Department of Health. (2018). *Clinical practice guidelines: Pregnancy care, economic analyses*.

understand our formal response may have contributed to this change. Nonetheless, there remains no specific recommendations about psychosocial support or key indicators related to the psychosocial aspects of prenatal diagnosis of a life-limiting anomaly.

- lack of data capture and reporting of psychosocial outcomes of women and families who have received unexpected news.
- no funding to include the impact of prenatal diagnosis in the update of the Mental Health Care in the Perinatal Period guidelines, as identified on Page 1.<sup>18</sup>
- lack of recommendations and action despite submissions to *the Victorian Inquiry into Perinatal Services* which highlighted the lack of relevant, accurate information to base important decisions, lack of appropriate support for those who receive a prenatal diagnosis of a life-limiting condition and continue pregnancy, inadequate care provision at the time of undergoing a termination of pregnancy<sup>19</sup> and concerns from sonographers about harming parents through inattention to the communication of unexpected news.<sup>20</sup>

This striking dearth in guidance and recommendations related to the psychosocial aspects of prenatal diagnosis underscores the importance for prenatal diagnosis to be included in this Guideline. Without this, the thousands of parents who receive unexpected news about the health, development or genetics of their unborn baby face inequities in accessing appropriate care, and their psychosocial health is at risk. The incidence of parents receiving a high-chance screening finding or a prenatal diagnosis is currently unknown. State and territory based congenital anomaly registers do not record the number of parents who receive unexpected findings that are not confirmed, and mandatory reporting of confirmed anomalies is typically only required from 20 weeks gestation. The most recent available report from Victoria suggests that 1 in 22 babies of all reported pregnancies (4.5%) had a major congenital anomaly. A major anomaly is classified as a structural or genetic anomaly that is associated with morbidity, mortality or disability. Unfortunately, this report is from 2015-16 period as there is a lag in reporting, like the congenital anomalies reporting by the Australian Institute of Health and Welfare in which 2016 was the most recent year reported. Despite the significant limitations of these reports, we know that;

- Over 8,900 (3%) of babies born in 2016 had a congenital anomaly which had significant medical, social or cosmetic outcomes,<sup>21</sup>
- Congenital anomalies were the most common cause of perinatal death in 2020, representing 33% of all perinatal death,<sup>22</sup>
- NIPT has led to an increase rate of prenatal diagnosis, such as the significantly increased rate of 47,XXY (Klinefelter syndrome) “from 0.8 per 10,000 births in 2005 to 4.3 per 10,000 births in 2020 ( $p < 0.0001$ )”.<sup>23</sup> There are many genetic and structural anomalies that are not life-limiting in nature

<sup>18</sup> Consultation draft guideline: Mental health care in the perinatal period, Australian clinical practice guideline. 2022 revision.

<sup>19</sup> Hodgson et al., Submission S073, Family and Community Development Committee.

<sup>20</sup> Parliament of Victoria: Family and Community Development Committee. (2018). Inquiry into perinatal services: Final report.

<sup>21</sup> Australian Institute of Health and Welfare. (2022). *Congenital anomalies 2016*.

<sup>22</sup> Australian Institute of Health and Welfare. (2020). *Australia's mothers and babies*.

<sup>23</sup> Loughry, L., Pynaker, C., White, M., Halliday, J. & Hui, L. (2022). State-wide increase in prenatal diagnosis of Klinefelter syndrome on amniocentesis and chronic villus sampling: Impact of non-invasive prenatal testing for sex chromosome conditions. *Prenatal Diagnosis*. <https://doi.org/10.1002/pd.6103>

and Klinefelter syndrome represents one of those, associated with a highly variable phenotype and as such presents with great uncertainty during the perinatal period.

- Expanding carrier screening programs will also include parents in the early stages of pregnancy, and as such will increase the number of parents who receive unexpected news. The lack of psychosocial support to make difficult decisions and cope with uncertainties or decisions surfaces moral and ethical issues.<sup>24</sup>

Antenatal screening technology has advanced faster and gained more attention and funding than the psychosocial implications and supports for parents who receive a high-chance screening finding or a prenatal diagnosis. Australian-based literature highlights the unmet psychosocial needs of parents who receive a prenatal diagnosis, whether they continue or end their pregnancies.<sup>25,26,27,28,29</sup>

The Guideline provides an important opportunity to begin to address the striking gap and can lead the way in ensuring that parents who receive unexpected news of a suspected or confirmed prenatal diagnosis receive care that recognises and supports their psychosocial health and well-being. In a current in-progress research project, we have identified influence of the Guideline within individual health service policies and procedures. These same policies and procedures overlook the psychosocial aspects of prenatal diagnosis and instead focus on the referral pathways for diagnostic and prognostic counselling, typically demonstrating that prenatal diagnosis means a disruption of pregnancy and birthing care and plans, interruption of continuity of care and alters pregnancy into a medical experience, which can impact psychosocial outcomes despite the pathway undertaken. There is significant potential for the Guideline to influence individual health service policy and procedures and lead to greater clinician awareness and improved care for parents who receive a prenatal diagnosis of a fetal anomaly.

---

<sup>24</sup> Samechi, A. (2022). Three-condition genetic carrier screening to become free. *RACGP NewsGP*. <https://www1.racgp.org.au/newsgp/clinical/three-condition-genetic-carrier-screening-to-becom>

<sup>25</sup> Marokakis, S., Kasparian, N. A., & Kennedy, S. E. (2017). Parents' perceptions of counselling following prenatal diagnosis of congenital anomalies of the kidney and urinary tract: a qualitative study. *BJU International*, 119(3), 474-481. <https://doi.org/10.1111/bju.13668>

<sup>26</sup> Hodgson, J. & McClaren, B.J. (2018). Parental experiences after prenatal diagnosis of a fetal abnormality. *Seminars in Fetal & Neonatal Medicine*, 23, 150-154. <https://doi.org/10.1016/j.siny.2017.11.009>

<sup>27</sup> Hodgson, J., Pitt, P., Metcalfe, S., Halliday, J., Menezes, M., Fisher, J., Hickerton, C., Petersen, K., & McClaren, B. (2016). Experiences of prenatal diagnosis and decision-making about termination of pregnancy: A qualitative study. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 56(6), 605-613. <https://doi.org/10.1111/ajo.12501>

<sup>28</sup> de-Vitry Smith, S., Dietsch, E., & Bonner, A. (2012). Parents' experience of time distortion following diagnosis of a serious or lethal fetal anomaly. *International Journal of Childbirth*, 2(4), 212-221. <https://doi.org/10.1891/2156-5287.2.4.212>

<sup>29</sup> Shakes, P., & Cashin, A. (2021). Mental health nursing and the prenatal diagnosis of a congenital anomaly; a narrative of experience. *Journal of Psychiatric and Mental Health Nursing*, 28(2), 271-277. <https://doi.org/10.1111/jpm.12645>

We have provided our recommendations for your consideration, as below. We have included our recommendation, followed by a suggested comment and reference/s.

## PART A — BACKGROUND INFORMATION

### 1 Mental health conditions in the perinatal period

#### 1.1 Understanding the woman's context

We recommend the inclusion of the heightened risk of prenatal onset anxiety disorders for women who experience pregnancy complications of moderate to high-risk:

- Women who experience moderate or high-risk maternal and fetal complications have are at five to seven times greater risk of developing prenatal onset anxiety disorders.<sup>30</sup>

#### 1.2 Prevalence and impact of maternal mental health conditions in the perinatal period

**Item 1.2.4:** We recommend expanding this item, *Experience of psychological birth trauma*, to include women who receive a prenatal diagnosis. We understand that the Australian Birth Trauma Association recognise trauma during pregnancy within their conceptualisation of birth trauma, however, if preferred the item headings could be changed to reflect the extension, such as *Experience of psychological birth trauma or trauma related to prenatal diagnosis*.

- Women who receive a prenatal diagnosis of a fetal anomaly experience shock and distress. In one study, the experience of receiving a prenatal diagnosis was found to meet the diagnostic classification of trauma within 88% of mothers.<sup>31</sup> The high incidence of trauma is further reflected in studies that have found 85% of women report re-experiencing symptoms of trauma<sup>32</sup>, and 35-39% of mothers were found to meet full diagnostic

<sup>30</sup> Fairbrother, N., Young, A.H., Zhang, A., Janssen, P. & Antony, M.M. (2017). The prevalence and incidence of perinatal anxiety disorders among women experiencing a medically complicated pregnancy. *Archives of Women's Mental Health*, 20. 311-319. <https://doi.org/10.1007/s00737-016-0704-7>

<sup>31</sup> Aite, L., Zaccara, A., Mirante, N., Nahom, A., Trucchi, A., Capolupo, I., & Bagolan, P. (2011). Antenatal diagnosis of congenital anomaly: a really traumatic experience? *Journal of Perinatology*, 31(12), 760-763. <https://doi.org/10.1038/jp.2011.22>

<sup>32</sup> Horsch, A., Brooks, C., & Fletcher, H. (2013). Maternal coping, appraisals and adjustment following diagnosis of fetal anomaly. *Prenatal Diagnosis*, 33(12), 1137-1145. <https://doi.org/10.1002/pd.4207>

criteria for PTSD.<sup>26,33</sup> Anxiety after a prenatal diagnosis was rated as moderate to severe in 1 in 2 women.<sup>34</sup> Furthermore, although limited by the small sample size, a prospective comparative study which employed validated measurement tools found mothers who received a prenatal diagnosis had a higher prevalence of depressive symptoms during pregnancy than women with a typically developing fetus, and a significantly increased rate of suicidal ideation.<sup>35</sup> Emerging evidence suggests maternal antenatal distress after a prenatal diagnosis of congenital heart disease is associated with impaired fetal neurodevelopment,<sup>36</sup> indicating potential long-term consequences of unmet psychosocial health needs of women continuing pregnancies after a fetal anomaly. Women who underwent a termination for medical reasons were found to experience higher anxiety and post-traumatic stress early in a subsequent pregnancy, when compared to women with a typically developing fetus.<sup>37</sup>

**Item 1.2.5:** We recommend including a comment of the impact of prenatal diagnosis of fathers and non-birthing parents.

- Fathers who experience adverse maternal, fetal or neonatal outcomes may experience a higher prevalence of depression and traumatic stress, inclusive of fathers who experience a termination for medical reasons.<sup>38</sup> Specifically, 83% of fathers experienced a prenatal diagnosis of a fetal anomaly as a traumatic event.<sup>39</sup>

## 2 Enabling effective care of mental health in the perinatal period

<sup>33</sup> Rychik, J., Donaghue, D. D., Levy, S., Fajardo, C., Combs, J., Zhang, X., Szwest, A., & Diamond, G. S. (2013). Maternal psychological stress after prenatal diagnosis of congenital heart disease. *Journal of Pediatrics*, 162(2), 302-307 e301. <https://doi.org/10.1016/j.jpeds.2012.07.023>

<sup>34</sup> Fontoura, F. C., Cardoso, M. V. L. M. L., Rodrigues, S. E., Almeida, P. C. d., & Carvalho, L. B. (2018). Anxiety of mothers of newborns with congenital malformations in the pre- and postnatal periods. *Revista Latino-Americana De Enfermagem*, 26, e3080-e3080. <https://doi.org/10.1590/15188345.2482.3080>

<sup>35</sup> Kaasen, A., Helbig, A., Malt, U. F., Naes, T., Skari, H., & Haugen, G. (2017). Maternal psychological responses during pregnancy after ultrasonographic detection of structural fetal anomalies: A prospective longitudinal observational study. *PLoS One*, 12(3), e0174412. <https://doi.org/10.1371/journal.pone.0174412>

<sup>36</sup> Wu, Y., Kapse, K., Jacobs, M., Niforatos-Andescavage, N., Donofrio, M. T., Krishnan, A., Vezina, G., Wessel, D., du Plessis, A., & Limperopoulos, C. (2020). Association of maternal psychological distress with in utero brain development in fetuses with congenital heart disease. *JAMA Pediatrics*, 174(3), e195316. <https://doi.org/10.1001/jamapediatrics.2019.5316>

<sup>37</sup> Beauquier-Maccotta, B., Shulz, J., De Wailly, D., Meriot, M.-E., Soubieux, M.-J., Ouss, L., Grosmaître, C., Salomon, L. J., Golse, B., Ville, Y., & Missonnier, S. (2022). Prenatal attachment, anxiety and grief during subsequent pregnancy after medical termination of pregnancy. Attachment to which child? *Journal of Gynecology Obstetrics and Human Reproduction*, 51(4). <https://doi.org/10.1016/j.jogoh.2022.102353>

<sup>38</sup> Kothari, A., Bruxner, G., Dulhunty, J.M., Ballard, E. & Callaway, L. (2022). Dads in distress: symptoms of depression and traumatic stress in fathers following poor fetal, neonatal, and maternal outcomes. *BMC Pregnancy and Childbirth*, 22, 956. <https://doi.org/10.1186/s12884-022-05288-5>

<sup>39</sup> Aite, L., Zaccara, A., Mirante, N., Nahom, A., Trucchi, A., Capolupo, I., & Bagolan, P. (2011). Antenatal diagnosis of congenital anomaly: a really traumatic experience? *Journal of Perinatology*, 31(12), 760-763. <https://doi.org/10.1038/jp.2011.22>

2.1 Therapeutic relationship
2.2 Care provision
2.3 Support and information
2.4 Continuity of care
We recommend an additional comment of the barriers to continuity of care for women with pregnancy complications, such as a prenatal diagnosis. <ul style="list-style-type: none"> <li>Some pregnancy experiences and complications, such as the prenatal diagnosis of a fetal anomaly, may disrupt continuity of care. Women with complicated pregnancies are at risk of falling through the gaps between different health providers, models of care and maternity services.<sup>40</sup></li> </ul>
<b>PART B — SCREENING AND PSYCHOSOCIAL ASSESSMENT</b>
<b>3 Considerations before screening and psychosocial assessment</b>
<b>4 Screening for depressive and anxiety disorders</b>
4.1 Screening for depression
4.2 Culturally appropriate screening for depression
4.3 Screening for anxiety
<b>5 Assessing psychosocial factors that affect mental health</b>

<sup>40</sup> Naughton, S.L., Harvey, C. & Baldwin, A. (2021). Providing women-centred care in complex pregnancy situations. *Midwifery*, 102, 103060. <https://doi.org/10.1016/j.midw.2021.103060>

5.1	Psychosocial assessment tools
5.2	Other considerations in psychosocial screening
<b>6</b>	<b>Assessing perinatal mental health in fathers and non-birthing partners</b>
5.1	Screening for depression and anxiety
5.2	Psychosocial screening
<b>7</b>	<b>Assessing mother-infant interaction and safety of the woman and infant</b>
7.1	Mother-infant interaction
	<p>We recommend the specific inclusion of prenatal diagnosis within Table 7.1, under the psychosocial risk factors. We make this recommendation due to the literature that indicates that bonding and attachment can be jeopardised in order to cope with unexpected news and uncertainty after a prenatal diagnosis. This addition may also prompt the consideration of prenatal diagnosis, so that professionals can be mindful in their use of language when talking about developmental outcomes and expectations or making an assessment about a mothers focus or worry about development.</p> <ul style="list-style-type: none"> <li>• Did the mother receive news of a fetal anomaly or variation during pregnancy?</li> </ul>
7.2	Risk to the infant
7.3	Risk of suicide
<b>8</b>	<b>Implementing psychosocial assessment and screening</b>

8.1	Incorporating psychosocial assessment and screening into routine practice
8.2	General approaches post-assessment
	We recommend the inclusion of prenatal diagnosis within the bracketed example of women without current symptoms but experiencing significant psychosocial risk.
	<i>Current line: <b>women without current symptoms but experiencing significant psychosocial risk</b> (e.g. a recent separation) may benefit from ongoing psychosocial support.</i>
	<ul style="list-style-type: none"> <li>• <b>women without current symptoms but experiencing significant psychosocial risk</b> (e.g. a recent separation, received a prenatal diagnosis) may benefit from ongoing psychosocial support.</li> </ul>
8.3	Referral and care pathways
8.4	Supporting emotional health and wellbeing
8.5	Women with complex presentations
<b>9</b>	<b>Practice summary — assessment and screening</b>
	PART C — PREVENTION AND TREATMENT
<b>10</b>	<b>General principles in prevention and treatment</b>
10.1	Providing information and advice
10.2	Planning care for women with mental health conditions

10.3 Use of pharmacological treatments
<p>We recommend wording changes to highlight autonomous decisions about antenatal screening and to address the potential psychosocial challenges if a fetal anomaly is identified. Guilt and self-blame is a commonly reported factor within the experience of receiving a prenatal diagnosis of a fetal anomaly,<sup>41</sup> and is likely to be more complicated for pregnant women who take such medication. The heightened complexity has not been specifically explored in the literature, as many studies, particularly those that seek to measure psychosocial outcomes after a prenatal diagnosis, exclude women with a history of mental health diagnoses.<sup>42</sup> Prenatal counselling is typically limited to diagnostic and prognostic counselling and the provision of pregnancy options. Given the likelihood of distress, it is pertinent to clearly recommend psychosocial support in the Guideline.</p> <p><i>Current: As there is a risk of major malformation associated with the use of some antipsychotics and anticonvulsants in the first trimester (see Chapter 12), it is important that the 13 week and 18–20 week ultrasound assessments are conducted so that major malformations may be identified. This enables women and their significant other(s) to consider their options (e.g. receive counselling regarding the option of termination) and plan for additional care if the pregnancy continues (e.g. specialist management of the pregnancy and the infant).</i></p> <ul style="list-style-type: none"> <li>As there is a risk of major malformation associated with the use of some antipsychotics and anticonvulsants in the first trimester (see Chapter 12), it is important to offer the woman ultrasound assessments at 13 week and 18–20 week to identify any major malformations. A finding of a fetal anomaly enables women and their significant other(s) to consider their options (e.g. receive counselling regarding the option of termination) and plan for additional care if the pregnancy continues (e.g. specialist management of the pregnancy and the infant). Psychosocial support should also be provided due to the potential for significant distress.</li> </ul>
10.4 Postnatal care and support
<b>11 Women with depressive and anxiety disorders</b>
11.1 Psychosocial and psychological interventions
11.2 Complementary therapies

<sup>41</sup> Hodgson, J. & McClaren, B.J. (2018). Parental experiences after prenatal diagnosis of a fetal abnormality. *Seminars in Fetal & Neonatal Medicine*, 23, 150-154.

<sup>42</sup> Shakes, P., & Cashin, A. (2021). Mental health nursing and the prenatal diagnosis of a congenital anomaly; a narrative of experience. *Journal of Psychiatric and Mental Health Nursing*, 28(2), 271-277. <https://doi.org/10.1111/jpm.12645>

11.3 Pharmacological treatments
<b>12 Women with severe mental illnesses: schizophrenia, bipolar disorder and postpartum psychosis</b>
12.1 Preconception planning
12.2 Considerations in providing antenatal and postnatal care
12.3 Psychosocial and psychological intervention
12.4 Pharmacological treatment
<b>13 Women with borderline personality disorder</b>
13.1 Considerations in providing antenatal and postnatal care
13.2 Psychosocial support and psychological treatments
13.3 Pharmacological treatment
<b>14 Women who experience psychological birth trauma</b>
14.1 Considerations in providing antenatal and postnatal care
14.2 Psychosocial support and psychological interventions

14.3 Pharmacological treatment
<b>15 Women who do not respond to psychological or pharmacological treatment</b>
15.1 Electroconvulsive therapy
15.1 Repetitive transcranial magnetic stimulation
<b>16 Practice summary — prevention and treatment</b>
<b>PART D: AREAS FOR FUTURE RESEARCH</b>
<p>We recommend the specific inclusion of the psychosocial aspects of prenatal diagnosis within the section that highlights potential areas for future development. The focus should be on models of care that act to prevent enduring psychosocial challenges through the provision of non-stigmatised, non-judgemental, women-centred care that reduces additional systemic complexities that further complicate the experience of receiving a prenatal diagnosis. The literature highlights that the care provided can influence psychosocial outcomes, indicating there is potential to prevent psychosocial challenges and long-term consequences rather than simply screen and treat them.</p> <ul style="list-style-type: none"> <li>• Models of perinatal care which are responsive to the dynamic and individual needs of women and families who receive a prenatal diagnosis of a fetal anomaly, to reduce distress, promote adaption and improve psychosocial outcomes.</li> </ul>
<b>APPENDICES</b>

Thank you again for the opportunity to respond the draft Guideline.

If you have any questions about this submission or our current research and training projects in development, please contact Pieta Shakes at [info@throughtheunexpected.org.au](mailto:info@throughtheunexpected.org.au)