



Office of the
Children's Guardian

Guidelines for Principal Officers

in relation to requests under the
Human Tissue Act 1983 to remove organ and
tissue from a deceased child or young person
in the care of the State

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The NSW Children's Guardian accredits agencies for the provision of services for children and young people in statutory out-of-home care¹ and adoption. Agencies that are accredited by the Children's Guardian are referred to as designated agencies or adoption agencies.

1. Purpose of these guidelines

The Principal Officer is the person with overall responsibility for supervising a designated agency's arrangements for providing statutory out-of-home care or adoption services.

Principal Officers of designated agencies have legal requirements under the *Children and Young Persons (Care and Protection) Act 1998* and the *Children and Young Persons (Care and Protection) Regulation 2012*. These requirements include immediate notification of a death of a child or young person in statutory out-of-home care to their parents, the NSW Children's Guardian and the NSW Coroner (section 172).

Information about notifying the Children's Guardian of a death of a child or young person in statutory out-of-home care is available on the [Office of the Children's Guardian's website notifications page](#).

2. Organ donation following the death of a child or young person

As only around one per cent of people in Australia will die in circumstances making them medically suitable to become donors, organ donation by children in the care of the State of NSW is a rare event.

However, under the *Human Tissue Act 1983* a request to remove organ and tissue from a deceased child or young person in statutory out-of-home care may be made for this purpose. These Guidelines provide procedure for Principal Officers of designated agencies should this occur.

3. Background

On 6 February 2007, a young person in the care of the State of NSW died. During this young person's lifetime, she had indicated a wish to donate her organs after her death. However as the law stood, no person was permitted to authorise the removal of tissue from a deceased child or young person in the care of the state even where both her birth parents and foster parents consented to the donation.

As a result of this, the NSW Government established the *Taskforce on Organ and Tissue Donation by Children and Young People in the Care of the State of NSW*. The Taskforce investigated

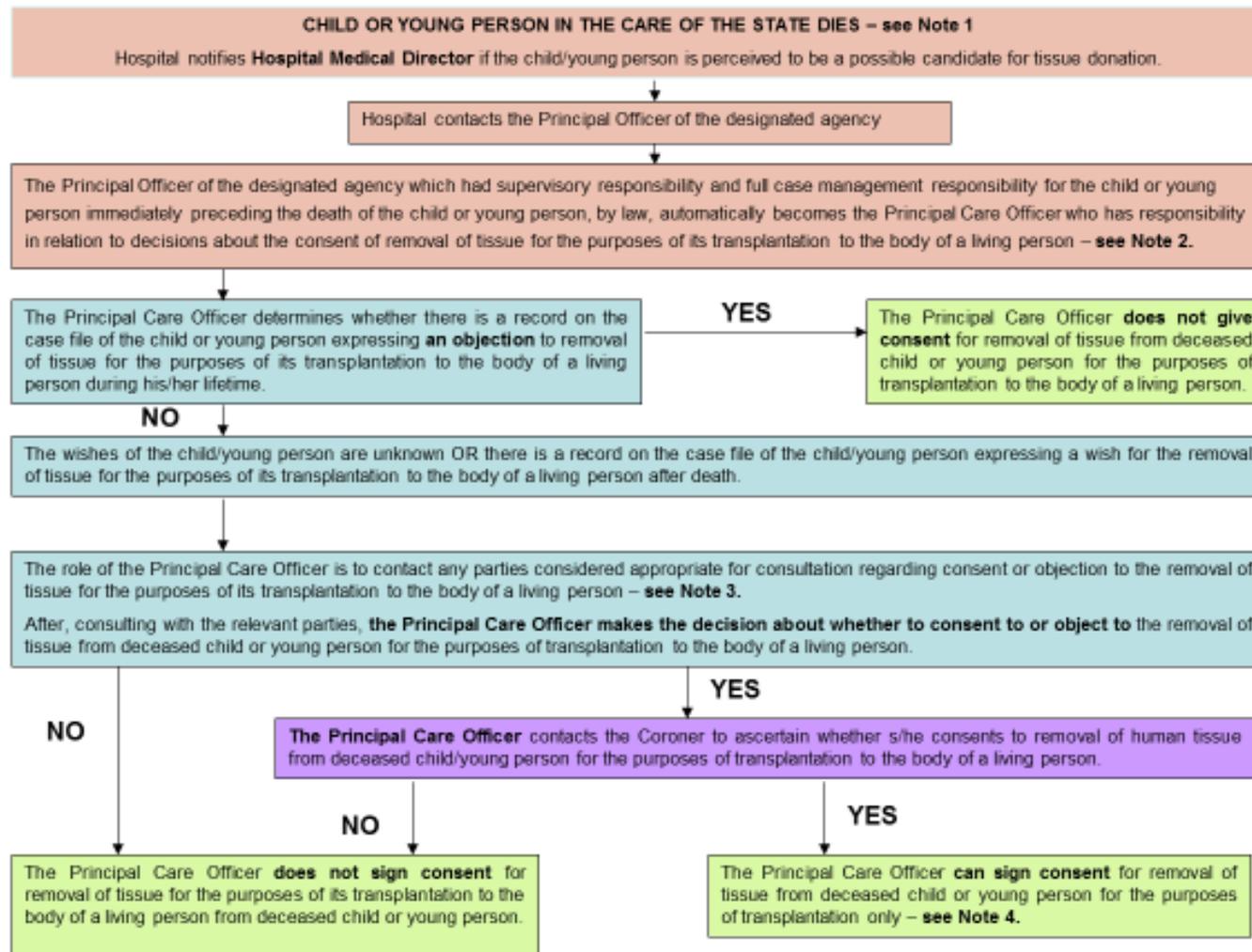
¹ Statutory out-of-home care is the care of children and young people who are under an order of the Children's Court, which has allocated parental responsibility to the Secretary or the Minister for Community Services.

possible changes to laws governing organ and tissue donation that would allow children in the care of the State to be considered eligible donors.

The Taskforce's report recommended amendments to the *Human Tissue Act 1983* to allow children/young people in the care of the State to be considered as eligible organ and tissue donors. The *Human Tissue Act 1983* was amended accordingly.

These procedures outline the steps a Principal Officer of a designated agency is to take under the *Human Tissue Act 1983* if contacted by a hospital.

4. Procedure for Principal Officers



Child or young person in statutory out-of-home care dies – see Note 1

Hospital notifies Hospital Medical Director if the child/young person is perceived to be a possible candidate for tissue donation.

Note 1: A child or young person is in the care of the State if either the Minister or the Secretary has **sole parental responsibility** in respect of the child or young person as per section 4(7) of the *Human Tissue Act 1983*.

For reasons of safeguards, the Principal Officer of the designated agency should check the case file record of the child or young person to confirm that the court order through which the child came into care places the child or young person under the sole parental responsibility of the Minister or the Secretary.

Hospital contacts the Principal Officer of the designated agency

The Principal Officer of the designated agency which had supervisory responsibility and full case management responsibility for the child or young person immediately preceding the death of the child or young person by law automatically becomes the Principal Care Officer who has responsibility in relation to decisions about the consent of removal of tissue for the purposes of its transplantation to the body of a living person – see Note 2.

Note 2: Designated agencies include government and non-government agencies. While a designated agency will always have supervisory responsibility in relation to a child or young person to whom it provides an out-of-home care placement, it may assume case management responsibility for that child or young person as well.

The Principal Officer of the designated agency which had supervisory responsibility for the child or young person automatically becomes the Principal Care Officer and has responsibility in relation to decisions about the consent for tissue removal **only where the designated agency has assumed full case management responsibility for the child or young person.**

Where the designated agency does not have case management responsibility, the Secretary of the Department (currently the Department of Communities and Justice) or their delegate, would assume the responsibility.

The Principal Officer determines whether there is a record on the case file of the child or young person expressing an objection to removal of tissue for the purposes of its transplantation to the body of a living person during his/her lifetime.

→ **YES:** The Principal Care Officer does not give consent for removal of tissue from deceased child or young person for the purposes of transplantation to the body of a living person.

→ **NO:** The wishes of the child/young person are unknown OR there is a record on the case file of the child/young person expressing a wish for the removal of tissue for the purposes of its transplantation to the body of a living person after death.

The role of the Principal Care Officer is to contact any parties considered appropriate for consultation regarding consent or objection to the removal of tissue for the purposes of its transplantation to the body of a living person – see Note 3.

After, consulting with the relevant parties, the **Principal Care Officer makes the decision about whether to consent to or object to the removal of tissue** from deceased child or young person for the purposes of transplantation to the body of a living person.

Note 3: Before deciding whether or not to give consent for the removal of tissue from the deceased child's or young person's body, the Principal Care Officer must use reasonable efforts to contact those persons who have been significant in the child's or young person's life and who the Principal Care Officer considers to be appropriate to assist in the decision making process.

Such persons may include:

- Birth parents
- Foster parents
- Extended family
- Any parties sharing aspects of parental responsibility for the child or young person
- If the child/young person is Aboriginal or Torres Strait Islander, appropriate persons from the child's or young person's Aboriginal/Torres Strait Islander community
- Other persons considered relevant by the Principal Care Officer.

The Principal Care Officer will determine whose approval is required and may determine that more than one person's approval is necessary. If any of those consulted are persons whose approval the Principal Care Officer considers should be obtained, the Principal Care Officer must not give consent unless that approval is obtained.

Principal Care Officers should record the actions that they have taken at each step in the decision making process and the details of any parties they contacted, or attempted to contact.

A Principal Care Officer must not give consent unless all relevant parties have been consulted and have given their approval to the organ donation.

→ **YES:** The Principal Care Officer contacts the Coroner to ascertain whether s/he consents to removal of human tissue from deceased child/young person for the purposes of transplantation to the body of a living person.

→ **NO:** The Principal Care Officer **does not sign consent** for removal of tissue for the purposes of its transplantation to the body of a living person from deceased child or young person.

→ **YES:** The Principal Care Officer **can sign consent** for removal of tissue from deceased child or young person for the purposes of transplantation only - see Note 4.

Note 4: While the Principal Care Officer can give consent, a Designated Officer for a hospital is still required to authorise removal of tissue from a deceased child's body. In order to provide such authorisation, the Designated Officer must be satisfied after making reasonable inquiries that the child or young person did not express objection during his or her lifetime about removal of tissue, and that the Principal Care Officer has given his or her consent to the removal of tissue from the child's body.

Under section 25 of the *Human Tissue Act 1983*, the consent of the Coroner must be obtained prior to the removal of tissue from the deceased child's or young person's body.

5. More information

For more information about these guidelines or other accreditation requirements for designated agencies providing statutory out-of-home care or adoption services, please email the Office of the Children's Guardian's Accreditation and Monitoring Team at accreditation@kidsguardian.nsw.gov.au or telephone (02) 8219 3796.

Information about the Office of the Children's Guardian's other regulatory responsibilities, including the Working With Children Check, Child Safe Organisations, registration and monitoring of voluntary out-of-home care and accreditation and monitoring of adoption services, is available at www.kidsguardian.nsw.gov.au

See also: *Human Tissue Act 1983*
Children and Young Persons (Care and Protection) Act 1998
Children and Young Persons (Care and Protection) Regulation 2012
[Fact Sheet: Principal Officers](#)