

GUIDELINES FOR CARE OF NEXT INFANT

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| 1 | Initial Issue | Nov 2010 |
| 2 | No changes to Guidelines. Format updated to current corporate template | April 2015 |
| 3 | Changes: inclusion of Care Of Next Infant (CONI) champions, identifying the importance of communication, clear clarification of roles of midwives and health visitors, clear guidance of the referral process, Equipment and record-keeping sections, and a clear section relating to Safeguarding. | 12/03/2024 |

Engagement & Consultation

Key Individuals/Groups Involved in Developing this Document

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| Health Visiting Team Leaders |
| Assistant Head of Public Health Nursing |
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Circulated to the following for Consultation

| Date | Role / Designation |
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| Dec 2023 | Head of Midwifery |
| Dec 2023 | Assistant Heads of Midwifery |
| Jan 2024 | Women and Children’s Policies & Procedures Group |
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1 Introduction

This Guideline has been developed to provide midwives, health visitors, paediatricians, paediatric nurses, neonatal nurses, GPs, and other relevant health professionals with the framework for the process to identify and enrol parents and families for the CONI (Care of Next Infant) programme and support them for the duration of the Programme.

The CONI programme was set up in 1988 and is run in partnership with the Lullaby Trust, managed by a national co-ordinator, and public health services. It provides support for families who have experienced or are at a higher risk of sudden infant death syndrome (SIDS) or sudden and unexpected baby death, and who are expecting or have given birth to a new baby. The CONI programme provides specialist advice, information and support to health professionals. They in turn, support bereaved families with their subsequent babies to help them enjoy the first year of their baby's life as these families are often very anxious (Lullaby Trust 2021a).

This document incorporates the values of the Health Board as it encourages us to work together as one team.

This document applies to all professionals involved in delivery of the CONI programme and clients who fit the criteria of the CONI programme. It is indiscriminate of different groups eg: race, gender, ethnicity, disability, language, religion, and beliefs. It applies in areas covered by Powys Teaching Health Board (PTHB).

2. Objective

- To ensure that there is good communication between midwives, CONI coordinators, CONI champions, health visitors, paediatricians, paediatric nurses, neonatal nurses, and general practitioners.
- To ensure that parents/families with personal history of SIDS are identified at the appropriate time for them to access the CONI

programme, so that they can receive appropriate and structured support.

- To guide and support the actions of professionals in terms of their responsibility to the client, and the actions they should take following identification of parent who has previously suffered the loss due to SIDS, Apparent Life-Threatening Event (ALTE) or Brief Resolved Unexplained Event (BRUE).
- To ensure that every identified parent and family is offered CONI support service, relevant to geographical area.
- To ensure parents and families receive adequate coordinated support which includes emotional support following a previous SID, ALTE or BRUE to help alleviate their fears through support and education.
- Additionally, CONI (previously CONI plus) can be offered to families who may have a special reason to be anxious, e.g.
 - Close relative of a baby that has suffered a sudden infant death.
 - Loss of a baby to other causes.
 - Have a baby who has experienced an apparent life-threatening event.

3. Definitions

PTHB – Powys Teaching Health Board

CONI – Care of Next Infant

SIDS – Sudden Infant Death Syndrome

ALTE – Apparently Life-Threatening Episode

EDD – Expected Date of Death

4. Role / Responsibilities

4.1 Head of Children's Nursing Service and Head of Midwifery

Is responsible for:

- Ensuring all staff read and understand this procedure.

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| | <ul style="list-style-type: none">• Arranging regular reviews to monitor compliance with this procedure. |
| | <p>4.2 Assistant Head of Public Health Nursing/Assistant Head of Midwifery</p> <p>Is responsible for:</p> <ul style="list-style-type: none">• Supporting the Head of Children’s Nursing Services and Head of Midwifery in ensuring there are regular reviews of this Guideline.• Ensuring that all staff are aware of and follow this Guideline. |
| | <p>4.3 PTHB Midwives and Health Visitors</p> <p>Are responsible for:</p> <ul style="list-style-type: none">• identifying possible users of this programme in the antenatal period.• Ensuring that identified women are referred to the local CONI Coordinator, North or South Powys.• Supporting professional training regarding CONI.• Contacting the mother at around 32–36 weeks (2 months prior to Expected Date of Delivery) following confirmation of continuation of pregnancy with midwife/health visitor. Families also to have the option of contact in early pregnancy for anxious parents, especially to address concerns regarding the previous SIDS. In certain circumstances this contact could be later, eg: movements into area, late bookers. |
| | <p>4.4 Midwives</p> <p>Are responsible for:</p> <ul style="list-style-type: none">• Identifying an antenatal parent who will benefit from the programme and meets the eligibility criteria at booking or at a later contact if not disclosed at booking.• Referring the pregnant mother for the CONI Scheme by sending a completed CONI – CARE OF NEXT INFANT - REFERRAL FORM |

| | |
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| | <p>(see Appendix A) to the local coordinator and documents in their hand-held midwifery records.</p> <ul style="list-style-type: none">• Notifying the Health Visitor of the birth of the baby. |
| | <p>4.5 Health Visitors</p> <p>Are responsible for:</p> <ul style="list-style-type: none">• Identifying a family who would benefit from the programme but has not previously been referred and ensuring that a referral using the CONI - Care of Next Infant- Referral Form is completed (Appendix B).• Informing the CONI Coordinator of the birth of the baby.• Ensuring that they take on the role of key worker for the care of the baby and the family after the baby is born. The Health Visitor will discuss any parental concerns as well as offering support, advice, and reassurance.• Informing the General Practitioner of a new referral to the CONI Scheme by completing the GP Notification which is provided as part of the programme. The health visitor will take the form to the GP Surgery.• Liaising with the local coordinator regarding resources required (ie: stationery, equipment) and arranging replacement of any faulty equipment.• Checking that the 6–12-week health review with the paediatrician/GP has taken place. If not, they will contact the local CONI coordinator.• Ensuring that, within 2 weeks of completion of the programme, the Health Visitor will collect the equipment and paperwork.• Evaluating parents' experience of CONI service at the end of the programme. The online form should be used, and information forwarded to the coordinator. It is not compulsory for the parents to complete the evaluation form, but it is encouraged and recommended. |

4.6 CONI Coordinator

Is responsible for:

- Ensuring that a visit is offered in the antenatal period and will support the local Health Visitor in the implementation of the programme.

5. Implementation

Referral to CONI Programme

- A referral can be made by any health professional who has contact with pregnant women or new parents who fit the criteria for the programme.
- The CONI programme is offered to parents expecting a new baby where either parent has previously experienced the sudden unexpected death of a child under 2 years of age. The programme may also be offered to support families with a surviving child (ren) from a multiple birth where one baby has died unexpectedly.
- The support provided by CONI may be extended to other families whose babies may be at increased risk of sudden infant death or who have reason to be anxious about their baby. Three groups have been identified who may have increased anxieties:
 - **Close relative** - Close family history of sudden unexpected death in infancy (SUDI) – a parental sibling/niece or nephew.
 - **Other baby deaths** - Parents have had a baby die from causes other than SIDA occurring after discharge from the neonatal or postnatal ward. Where anxiety persists, CONI may provide appropriate support.
 - **Apparent Life-Threatening Event (ALTE)/ Brief Resolved Unexplained Event (BRUE)** - Where a baby has suffered an apparently life-threatening event (ALTE)/ brief resolved unexplained event (BRUE). They can have fears about the survival of their baby that persist for many weeks/months following the event. Any episode should be investigated, but for as many as half of such events, no cause will be found. These babies are known to be at increased risk of mortality.

See pathway for referral to the CONI service during the antenatal period (Appendix A) and following ALTE (Appendix B).

The central organisation of CONI is funded by The Lullaby Trust and is managed by a National Coordinator.

6. Methods of Support for Families

The Health Visitor provides the primary support for each family; however, they can also be offered the following:

- Regular weekly contact in the home with the family's own health visitor, with a passport to the General Practitioner and fast access to an acute Paediatrician, to be organised by the family HV.
- Symptom diaries are available to assist parents to recognise the changes in their baby's health and help them to raise concerns with their Health Visitor at the regular visit. They also create opportunities for health education.
- Baby check leaflet is available to assess severity of signs and symptoms and indicate when the baby should be seen by a doctor.
- Weighing – regular weighing of the baby in the home by the Health Visitor, and the weights recorded on the Sheffield weight charts as well as the personal child health record centile chart (red book).
- Respiration monitoring – provision of a respiration monitor for parental reassurance. Alarm provided by PTHB, or family nominated for a single use monitor via the Lullaby Trust.
- Room thermometers – parents need to be aware of the room temperature and adjust bedding and clothing appropriately.

Parents are helped to select a package of support measures as above and enrolled on to the scheme by the CONI Coordinator.

The support is offered until the baby is 6 months or 2 months beyond the age at death of the previous baby or the last ALTE event.

The family is offered a home visit by the CONI Coordinator, who will distribute the equipment and paperwork. The respiration monitor is supplied by the coordinator.

Resuscitation training is organised by the family Health Visitor via a District General Hospital, or the Powys Health Board resuscitation trainers, or the CONI coordinators. CPR training may also be accessed on-line via Saint Johns or BLISS.

Ongoing evaluation of the CONI service is very important, thus when the baby is about 6 months old, the family are encouraged to feedback via an online system.

All registered practitioners should access appropriate safeguarding supervision and training as per guidance. Safeguarding Supervision (sharepoint.com).

7. Training

- CONI Coordinators to attend one day initial training followed by annual regional meetings.
- PTHB CONI Coordinators to update colleagues as new information becomes available.

8. Equipment

- The movement monitor to be tested after each child by the Local CONI Coordinator using the manufacturer's guidelines. Monitors should be cleaned between clients using local guidelines.
- To be serviced regularly by Avensys UK Ltd, as recommended by manufacturer.
- Any fault to be checked by Avensys UK Ltd.
- When not in use movement monitors are to be kept by the CONI Coordinators.

9. Record-Keeping

- There should be a good standard of record keeping in line with The Nursing and Midwifery Council's Code (NMC 2018). For Health Visitors this will be 'All Wales Health Visiting Specialist Community Public Health Nursing Team Standard Operational Procedure for Record Keeping and Documentation' (PTHB, 2021).
- Plan of care to be recorded in Health Visiting documents/records by Health Visitor and in Personal Child Health Record (PCHR red book).
- Coordinators to keep own record until infant discharged from programme.

- CONI Healthcare Passport to be placed in the Child's Personal Child Health Record (Red Book) and to be removed at the end of the programme.

10. Safeguarding

If any safeguarding concerns or significant risk factors are identified for a child or young person, practitioners must follow Wales Safeguarding Procedures (2019) and SGP036 Safeguarding Policy Policies & Written Control Documents - SGP 036 Safeguarding Policy.pdf (sharepoint.com). Advice and support concerning any safeguarding issue can be sought from PTHB Safeguarding Team via the Safeguarding Hub on 01686 252806 or email PowysTHB.Safeguarding@wales.nhs.uk (Monday-Friday 09:00-17:00, excluding Bank Holidays). Outside of office hours, Local Authority can be contacted on 0345 0544 847 or contact Silver on Call. All registered practitioners should access appropriate safeguarding supervision and training as per guidance. Safeguarding Supervision (sharepoint.com).

11. Monitoring Compliance / Audit

CONI is a national organisation, producing ongoing research and evaluation of the Programme. An annual audit is undertaken by the PTHB CONI Co- coordinators. National statistics are reported annually.

12. Review and Change Control

This document will be reviewed every three years or earlier should audit results or changes to legislation/practice within the PTHB indicate otherwise.

13. References / Bibliography

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(Accessed:03 November 2023).

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Lullaby Trust (2021b) *The Lullaby Trust – Care of Next Infant (CONI)*. Available at:

<https://www.lullabytrust.org.uk/wp-content/uploads/new-CONI-leaflet-2020-FINAL.pdf> (Accessed: 03 November 2023).

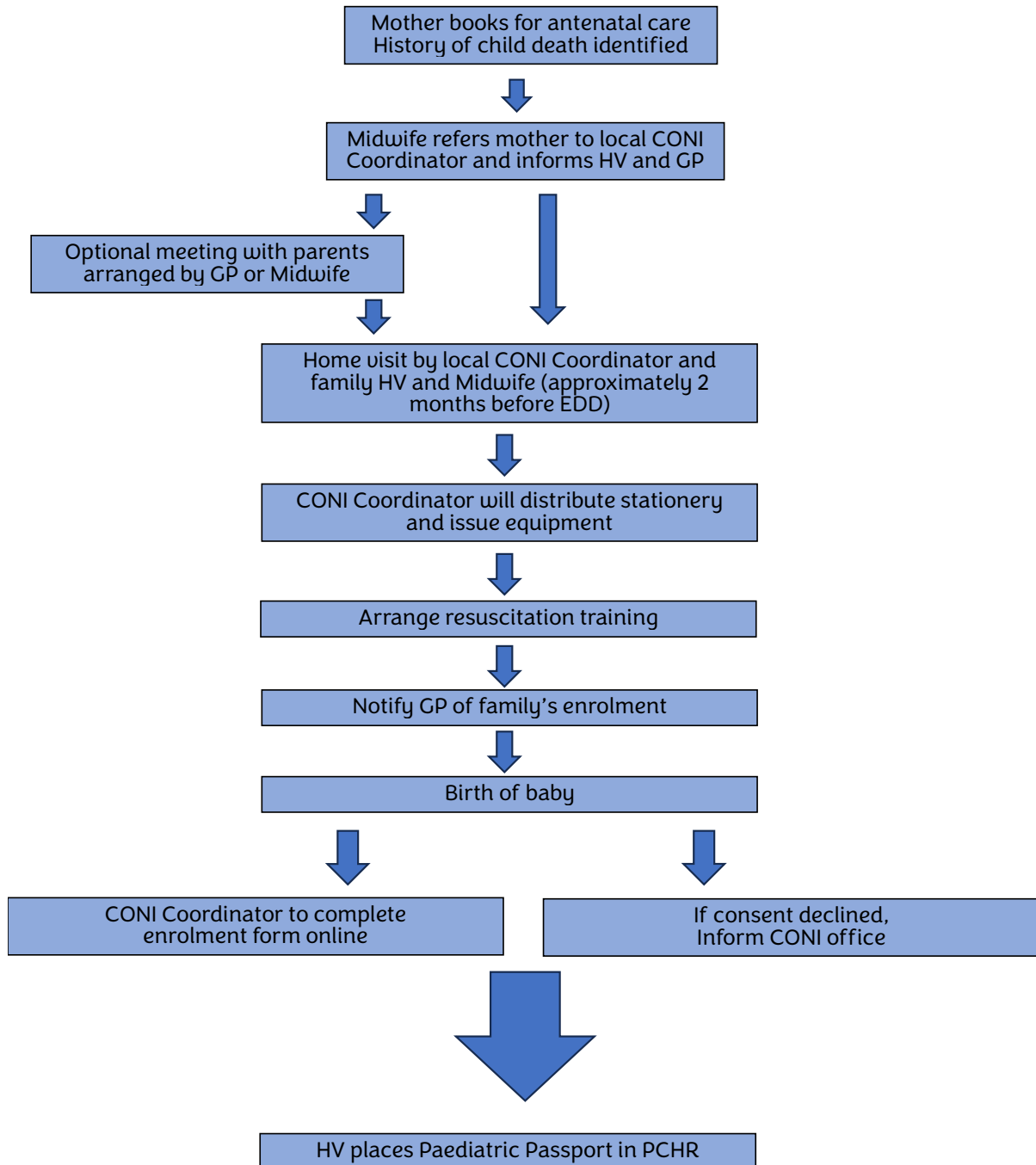
Nursing and Midwifery Council (2018) *The code: professional standards of practice and behaviour for nurses, midwives and nursing associates*. Available at:

<https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf>

(Accessed: 03 November 2023).

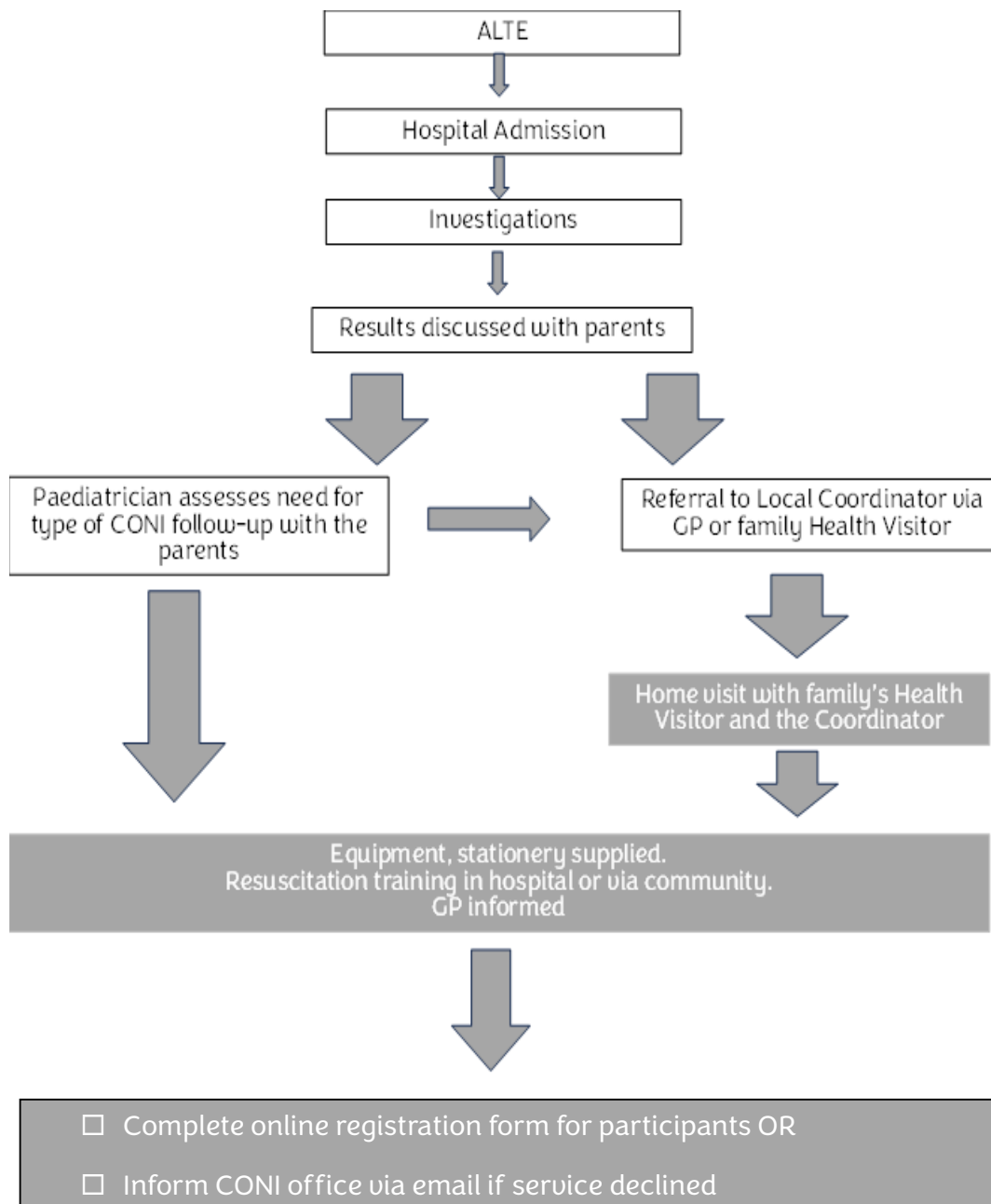
'All Wales Health Visiting Specialist Community Public Health Nursing Team Standard Operational Procedure for Record Keeping and Documentation' PTHB 2021

Referral to CONI Service





Pathway Following an Apparently Life-Threatening Episode (ALTE)



Appendix C
Ffurflen Ymrwymo - Benthg Cyfarpar
Indemnity Form-Loan of Equipment



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

Dylid defnyddio'r ffurflen hon wrth fenthyca offer at ddefnydd cleifion
This form should be used when issuing equipment for patients own use

| | | | |
|--|--|--|--|
| Yr Adran a Benthycwyd Department of Issue | | | |
| Cyswllt yr Adran (enw a swydd) | | Rhif Ffôn Cyswllt Yr Adran | |
| Department Contact (name designation) | | Department Contact Telephone Number | |
| Math o Gyfarpar / Disgrifiad Equipment Type / Description | | | |
| Rhif y Cyfarpar Serial Number | | | |
| Rhif yr Ased (<i>Ile bo'n briodol</i>) Asset Number (<i>where applicable</i>) | | | |
| Dyddiad Benthgyca Date Loaned | | | |
| Dyddiad Dychwelwyd Date Returned | | | |
| Dyddiad rhaid gwasanaethu'r Cyfarpar Date Equipment due for service | dd/mm/bbbb dd/mm/yyyy Dylai'r gwasanaeth cysylltu â'r claf a darparwr y gwasanaeth i sicrhau bod y cyfarpar ar gael cyn y dyddiad hwn. Service to liaise with patient & service provider to make equipment available before date. | | |
| Enw'r Claf Patients Name | | | |
| Cyfeiriad y Claf | | | |

| | | | |
|---|---|--|--|
| Patients Address | | | |
| Rhif Ffôn Telephone Number | | Rhif Ffôn Symudol Mobile Telephone Number | |
| Manylion Cyswllt y Gofalwr (<i>os yw'n berthnasol</i>) Contact Details of Carer (<i>if applicable</i>) | | | |
| Gwybodaeth ychwanegol lle bo angen Additional information if required | | | |
| Datganiad | <p>Rwy'n cydnabod fy mod i wedi derbyn yr offer uchod ar fenthyg mewn cyflwr gweithio glân.</p> <p>Rwy'n deall bod yr offer yn parhau i fod yn eiddo i Fwrdd Iechyd Addysgu Powys ac rwy'n cytuno:</p> <ul style="list-style-type: none"> • i ddychwelyd yr offer yn lân, yn gweithio'n iawn ar ddiwedd cyfnod y benthyciad • i beidio â gwneud unrhyw newidiadau i'r offer • Peidio ag ychwanegu addurn personol h.y. sticeri • Peidio ag ysgrifennu ar yr offer • Byddaf yn atebol am unrhyw gostau a godir os bydd yr offer yn cael ei ddifrodi neu ei golli tra yn fy meddiant | | |
| Declaration | <p>I acknowledge receipt of the above equipment on loan in a clean working condition.</p> <p>I understand that the equipment remains the property of Powys Teaching Health Board and I agree:</p> <ul style="list-style-type: none"> • to return the equipment in clean, working order at the end of the loan period • not to make any alterations to the equipment • Not to add personal decoration i.e. stickers • Not to write on the equipment <p>I will be held liable for any charges incurred if the equipment is damaged or lost while in possession</p> | | |
| Llofnod y Claf | | | |

| | | | |
|---|--|---|--|
| Patient Signature | | | |
| Enw'r Aelod o Staff Staff Name | | Llofnod yr Aelod o Staff Staff Signature | |
| Swydd yr Aelod o Staff Staff Designation | | | |

Y gwasanaeth i sicrhau bod yr wybodaeth ychwanegol hefyd yn cynnwys:
Service to ensure additional information also includes:

- Cyngor ar lanhau a llawlyfr / cyfarwyddiadau ar ddefnyddio'r offer | Cleaning advice & equipment user manual / instructions