CHAPTER 10: ADHERENCE, TREATMENT COMPLETION AND FOLLOW-UP

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SUMMARY OF RECOMMENDATIONS

- The treating physician and clinical team should work with the person diagnosed with TB disease to develop a health and social care plan and support them to complete treatment successfully. The health and social care plan should take relevant social, cultural and financial factors into account.
- All persons diagnosed with TB disease (particularly those in early stages of treatment) should receive Directly Observed Therapy (DOT) or Video Observed Therapy (VOT). Priority for DOT/VOT should be given to persons with drug-resistant TB and/or whose medical or social circumstances indicate that adhering to/engaging with treatment may be challenging.
- Treating physicians and clinical teams should aim to find and contact any person with TB disease who misses an appointment(s), are lost to follow-up, or who disengage from services before completing diagnostic investigations.
- Multidisciplinary teams should implement interventions to support people to follow the treatment plan and prevent people stopping treatment early.
- Continuity of treatment for prisoners and persons detained should be ensured following arrival at a Prison or Place of Detention (PPD), in the event of a transfer, or when nearing release from a PPD.

10.1 Introduction

Currently in Ireland, most cases of TB disease attend either respiratory or infectious disease services for clinical management.

To achieve the End TB Strategy goal of ≥90% TB treatment success rate (effectively TB completion rate) requires a multidisciplinary approach and a recognition of the role of enablers and barriers to completion of treatment for individual patients.

Some of the strategic actions of Ireland's first national **TB Strategy** are particularly relevant to improving adherence and completion of treatment (1). These include developing and funding the provision of interventions that support adherence to treatment such as Directly Observed Therapy (DOT), implementing a national Video Observed Therapy (VOT) programme, developing peer-delivered patient support programmes as part of TB care, and providing patients with shorter more tolerable treatment regimens. Active case management is key to treatment completion. The strategy also recognises that some factors that contribute to adherence lie outside of the health sector, including poor social supports, housing, welfare assistance, etc.

10.2 Improving adherence: case management including directly observed therapy (DOT)

The treating physician and clinical team should work with the person diagnosed with TB disease to develop a health and social care plan and support them to complete treatment successfully. The following steps should be taken by the treating physician and clinical team:

- Conduct a risk assessment for every person with TB disease, to identify their health and social care needs, e.g. housing, and support structures; and whether they should be prioritised for enhanced case management including directly observed therapy (DOT) and video observed therapy (VOT).
- Engage with interpretation services as required
- Educate the person about TB and the treatment; check their understanding of this
- Develop an individual care plan after discussion with the person and their support network, if appropriate.
- Gain the person's consent to the plan and agree a review date (for example, when moving from initiation to maintenance, or at each contact to ensure the person's needs are being met)
- Coordinate discharge planning, especially for people on DOT or VOT, especially as pertains to housing, ability to travel to clinic and language barriers.

- Involve representatives from other allied professions and key workers from all organisations who work with the person, if appropriate, with the consent of the person.
- Explore appropriate ways that peer support workers and voluntary organisations can provide support.

10.2.1 DOT/VOT

All persons diagnosed with TB disease should receive DOT or VOT, especially in the early stages of treatment. Where resources are scarce, priority for DOT/VOT should be given to those patients with drug-resistant TB and/or those patients whose medical or social circumstances indicate that adhering to/engaging with may be challenging. The following persons should be offered DOT/VOT as a priority:

- Person who experiences (or has experienced in the past) challenges in adhering to TB treatment
- Person who has been treated previously for TB
- Person with experience of homelessness
- Person who has a history of using drugs or of alcohol dependence
- Person who is in prison or a place of detention, or has been in the past 5 years
- Person with a major psychiatric, memory or cognitive disorder
- Person not accepting of their TB diagnosis
- Person with multidrug-resistant TB (MDR-TB) or extensively drug-resistant TB (XDR-TB).
- Person who is too ill to self-administer the TB treatment themselves.
- Persons for whom other barriers may exist, see **section 10.2.2.**

In children with TB disease, whose parents are any of the persons outlined above, offer DOT or VOT as part of enhanced case management and include advice and support to enable treatment completion.

The need for DOT/VOT should be re-evaluated throughout the course of TB treatment.

10.2.2 Developing the health and social care plan

Treating physicians and clinical team should ensure the health and social care plan (particularly if DOT is needed) identifies potential challenges or circumstances that a person may experience that could impact on their ability to attend for diagnostic testing or follow a treatment plan, and enablers or supports that might be needed to engage with care.

Treating physicians and clinical teams should consider **the following factors** and any competing demands, priorities and urgencies, when developing the health and social care plan:

- **Demographic factors**: Age, nationality, country/ place of birth, length of time in Ireland,
- **Household/ family unit**: single adult vs single-headed household with children; caring responsibilities (e.g. feasibility of attending appointments if cannot bring children with)
- **Psychological health**: Mental health conditions, fear, past experience of trauma
- **Substance misuse**: Drug or alcohol use impacting on ability to engage with treatment/ care
- **HIV, hepatitis B and C status** (and need for testing if unknown)
- **Other health conditions**: Co-existing physical or mental health or psychological or cognitive issues
- **All current medications and prescribing regimens**: prescription medications, non-prescription (OTC) medication, any herbal remedies (that might impact on the metabolism/ clearance of TB medication, or interact with TB medications); tablet burden and complex regimens leading to difficulty managing doses
- **Cultural beliefs and barriers**: Stigma, traditional health beliefs, fear of discrimination
- **Communication factors**: Language proficiency (speaking, reading, comprehension), literacy levels (general literacy, health literacy and digital literacy), cognitive impairment
- **Housing and accommodation**: Including homelessness or housing precarity, or children in care; living in a congregate accommodation setting (e.g. State-provided accommodation for refugees or applicants seeking protection, emergency accommodation for people experiencing homelessness or family hub, shelter/ refuge).
- **Mobility and transport needs**: Access to treatment services; distance from clinic or hospital, transport links (frequency, timing with regard to clinic appointments), need for special transport (e.g. wheelchair accessible)
- **Financial or employment concerns**: Access to the labour market (e.g. need for work permit if a migrant), type of employment (e.g. zero hours contract), cost and accessibility of travel, loss of income, time off work
- **Entitlement to benefits**: Social welfare entitlements and access (e.g. for people seeking or granted protection in Ireland), financial insecurity (2).
- **Immigration or legal status**: Visa status, risk of deportation, relocation, or legal barriers

- **Criminal justice system involvement**: History of incarceration or ongoing legal matters.

The health and social care plan should:

- State **who** will be observing the person's treatment and **where** (if the person is having DOT this should be provided, if possible, by linking with existing services that the person is already engaged with, for example, a methadone clinic). Consider potential for choice or flexibility in when, where and with whom appointments take place.
- Include actions to take if contact with the person is lost or the person is 'missing' for example, getting an email address for the person (in case they lose their phone), or keeping details of people who might be able to help re-establish contact. See section 10.2.3.'
- Refer to, and be coordinated with, any other care plan already established for the person, and with those care providers
- Define the support needed to address any unmet health and social care needs (for example, support to gain housing or other benefits, or to help them access other health or social care services)
- Include a commitment from the person to complete their TB treatment
- Be supported by frequent contact with any key workers or peer workers who support the person.
- Be cognisant of the stigma associated with TB, particularly in minority ethnic groups

10.2.3 Lost to follow-up

Treating physicians and clinical teams should aim to find and contact any person with TB disease who misses an appointment or appointments, are lost to follow-up or who disengage from services before completing diagnostic investigations and/or TB treatment (3, 4). Where the clinical team fail to find the person, they should liaise with regional Public Health Departments, GPs, the referring organisation(s) and other appropriate services (for example, regional Social Inclusion, homeless services, or other relevant services that might be able to help in finding the person).

10.3 Strategies to support adherence to follow-up plan

To support engagement with their treatment plan, the person with TB disease should be involved in treatment decisions from the start. The importance of following the treatment plan should be emphasised when agreeing the regimen and appropriate education provided.

Multidisciplinary teams should implement interventions to support people to follow the treatment plan and prevent people stopping treatment early. **These could include:**

- Ensure sufficient information is collected at the initial appointment to enable follow-up (e.g. email/ mobile phone(s) details of the person and any key family members, key workers etc., preferred means of contact (e.g. SMS, email, phone), need for translation/interpretation)
- Reminder letters (if in a fixed abode), printed information (consider literacy/language needs) or infographics, telephone calls, texts and apps using an appropriate language
- Health education counselling and patient-centred interviews
- Tailored health education materials from quality sources in an accessible format given the barriers that the individual may experience
- Home visits with consideration of stigma and confidentiality
- Checking with pharmacy if prescription is being dispensed, pill monitoring and therapeutic drug monitoring, where indicated
- Access to free TB treatment or prophylaxis for everyone, and information about help with paying for prescriptions[1]
- Social and psychological support (including culturally sensitive management and broader social support)
- Advice and support for parents/guardians and carers
- Enablers to help people follow their treatment regimen.

10.4 Prisons and Places of Detention (PPD)

- On arrival at a prison or place of detention (PPD), to ensure continuity of treatment the admission health assessment should ask all persons detained (including those being transferred from other establishments) about any current diagnosis of TB, TB medication, or history of symptoms that may indicate TB disease.

[1] In line with the Infectious Diseases Regulations 1981, medication for Notifiable Diseases such as TB are provided free of charge, regardless of scheme.

- Prison staff should inform the treating clinical team and public health of planned transfer or release once they become aware.
- PPDs should ensure treating physician and clinical team(s) have access to persons being detained who need treatment (for example, by being given security clearance).
- All persons being detained receiving treatment for TB disease are required to have directly observed therapy. (DOT). with an awareness by those supervising treatment of the potential treatment side effects.
- Health services at PPDs should have contingency, liaison and handover arrangements to ensure continuity of care before any person being detained on TB treatment is transferred between prisons or released. In addition, other agencies working with prisoners or detainees should also be involved in this planning.
- Healthcare services for prisons and places of detention should liaise with the named treating physician and their clinical team to ensure contingency plans for continuation of treatment are drawn up for prisoners and detainees with TB.
- Persons detained who are nearing release, particularly those in prison, and who require continuation of their TB treatment, should have a bespoke care plan put in place with input from various stakeholders (IPS, prison in-reach services and community services) to ensure a seamless transition of care for the patient. This care plan should take into account the individual's social circumstances and include stable accommodation for the patient along with easy access to treatment and follow up in the community
- Treating physicians and clinical teams should ensure DOT/VOT is arranged for prisoners or detainees being treated for TB after their release. This should be available close to where they will live in the community.

10.5 Managing side-effects of treatment for TB

In people who have experienced a treatment interruption because of a reaction such as drug-induced hepatotoxicity, expert specialist opinion should be sought.

If another reaction of a similar or greater severity occurs because of reintroducing a particular drug, do not give that drug in future regimens and consider extending the total regimen accordingly.

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