Research Request – Learner Driver in Australia

Brief

Statistics and research to support the development of an NDIS funding position or at least and advice position.

For a Learner (Class C – car) driver in Australia – What are the percentage of learners who access driving lessons (as opposed to learning from family/friends)?

1.) For Learner (Class C – car) driver's doing the log book system – How many driving lessons do they usually require?

2.) For a Learner (Class C – car) driver, not doing a log book system but instead the state on-road licensing test - How many driving lessons do they usually require?

3.) Are there any differences (patterns) between different Australian states regarding driving instructor usage?

4.) Is there any evidence regarding the number of lessons an adult usually requires to learn to drive with a left accelerator in auto car as a new driver?

5.) Is there any evidence regarding the number of lessons an adult usually requires to re-learn to drive with a left accelerator in auto car (rather than a right one) as an existing driver?

6.) Is there any evidence regarding the maximum number of driving lessons funded by other funding agencies (eg TAC, Lifetime support scheme, DVA etc…) prior to them requiring further evidence (- if so what is the required evidence - ? a Driver Trained OT on -road assessment review)

7.) Is there any evidence regarding the position in regard to funding Learner driving lessons for other funding agencies (eg TAC, Lifetime support scheme, DVA etc…). Do they consider whether some or all of this is an everyday cost for consumers and therefore not cover it.

Date	July, 2020
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Please note:

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The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters.

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Australia's National Driver Licensing Scheme

In 1997, Australia implemented a National Driver Licensing Scheme (NDLS), establishing a single driver licence classification structure, eligibility criteria and a uniform set of requirements for key driver licensing transactions including the issue, variation, renewal, suspension and cancellation of licences.

Although Australia operates a federated licensing scheme (administered by the individual states and territories), the NDLS has been adopted by all Australian jurisdictions and, as a result, facilitates the mutual recognition between Australian jurisdictions of driver licences when transferring between jurisdictions. [1]

Australia's standard graduated licensing system (GLS) for cars

All Australian jurisdictions have introduced a GLS for novice drivers. The fundamental components of Australia's standard GLS policy framework are outlined below. All Australian jurisdictions currently meet or exceed these requirements. [1]

GLS requirements:

- Learner permit at 16 years – supervised driving required

- 12 months minimum holding of learner permit
- Requirement to undertake at least 50 hours supervised driving recorded in a log book
- Practical on-road test to achieve solo unsupervised licence
- Hazard Perception Test as part of GLS
- Solo licensing from 17 years
- Zero Blood Alcohol Content (BAC) and no hand held mobiles during entire learner/provisional period
- Lower demerit point threshold for novice drivers
- Community education about risks associated with:
  - Novice drivers and late night driving and carrying multiple passengers
  - Young drivers on a full licence and drink driving
- Support programs to assist disadvantaged drivers to progress.

Learners who access driving lessons with professional instructors as opposed to family/friends

No research or statistics could be sourced indicating learners who access driving lessons with professional instructors as opposed to family/friends.

In 2013 The Centre for Accident Research & Road Safety – Queensland, published a series of three reports which examined education and training for novice drivers. The third and final report [2] provided an overview of the graduated driver licensing (GDL) system and outlines the expert opinion of four international novice driver experts about the potential road safety impacts of different training approaches if applied to the GDL system in place within Queensland.

In looking at supervised on road practice the report indicated that *"All of the experts were in agreement that this is an effective way for the learner to gain experience and that there is strong potential for positive road safety effects in particular because of the potential to extend the learner phase using a mandated hours requirement. It was recognised that a certain amount of practice will be necessary before road safety effects can be realised, however, experts noted that there is no clear consensus in the literature as to how many hours this should be".*

The report also looked at the advantages and disadvantages of professional instructor lessons as opposed to supervision by family/friends with the following observations:

<u>Advantages</u>

- Exposes learners to practice driving under supervision which has a low crash risk.
- Allows gradual progression of practice from low crash risk (e.g. car parks) to higher risk conditions (e.g. night time driving).
- Allows parents to judge if the novice is ready to take their test.
- Increasing quantity of private supervision during learner phase is the most investigated and promoted way to reduce P1 crashes and has been shown to be effective at reducing crash risk in the first 2 unsupervised years.

- Without private supervision learners would likely rely on professional lessons, which often lack variety.
- Research suggests bad habits picked up from private supervisors does not outweigh the overall benefits, and likely could be addressed by good professional instruction.
- Required 100+ hours has potential to delay licensing which has safety benefits.

Disadvantages

- Parents do not always have sufficient tools to assist them as supervisors.
- Not all parents are good drivers or good teachers. Learners may adopt poor/unsafe/risky driving from a private supervisor.
- It is not clear from research the extent to which supervised driving experience translates into safer driving when unsupervised.
- Effects are only found if supervised practice is for a longer rather than shorter time/distance travelled.
- Required 100+ hours results in more practice of novices but puts a strain on some families.

Number of Lessons: Log Book System/State on-road Licensing Test and Driving Instructor Usage

- No state stipulates the number of driving lessons required. Instead, most states stipulate the minimum number of hours of supervised driving which needs to be recorded in a log book.

- It appears to be recognized that the number of lessons required depends on the individual driver's skills, confidence and other factors.

- The number of hours required varies from state to state and varies according the age of the driver. In some states a log book does not need to be completed if the driver is over a certain age.

- For all states, it appears there are no requirements regarding number of driving lessons for Learner Drivers not doing a log book system but instead the state on-road licensing test.

- In all states anyone holding an appropriate licence can supervise/instruct the learning driver. No states stipulate the use a professional driving instructor. Only one state (NSW) gives an incentive to drivers to use a professional instructor by offering bonus log book hours.

Below is table summarizing the general requirements per state for log book systems and driver instructor usage.

Australian State & Link to authority responsible for driver licensing functions	LOG BOOK SYSTEM	Driving Instructor Usage
NSW: Roads and Maritime Services New South Wales	**AGE**: Under the age of **25** must complete a minimum of 120 hours of supervised driving experience (including at least 20 hours at night). Aged 25 or older doesn't need to fill out a log book or complete any minimum amount of supervised driving. **LOG BOOK:** Hours must be recorded in a paper log book or log book app. Exemptions to the 120 hours include Previously held a NSW or interstate driver licence, other than a learner licence Previously held an overseas licence, other than a learner licence Hold an overseas licence, other than a learner licence, and are issued with a learner licence after failing one driving test Are specifically exempted by Roads and Maritime Services.	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor No stipulation to use a professional driving instructor. There is a 3 for1 bonus hours incentive: If Lerner has lessons with a professional driving instructor: for every 1 hour structured driving lesson, Lerner can record 3 hours driving experience in their log book.
VIC: VicRoads	**AGE**: Under the age of **21** must complete a minimum of 120 hours of supervised driving experience (including at least 20 hours at night). Aged 21 or older doesn't need to fill out a log book or complete any minimum amount of supervised driving. **LOG BOOK:** Hours must be recorded in a paper log book or log book app. Exemptions to the 120 hours include: If the nature of your essential activities, occupation, employment or family circumstances means that 120 hours of supervised driving would cause you or your family undue hardship. If you have sufficient previous driving experience (interstate and overseas experience will be considered).	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor No stipulation to use a professional driving instructor
QLD: Department of Transport and Main Roads Queensland	**AGE**: Under the age of **25** must complete a minimum of 100 hours of supervised driving experience (including at least 10 hours at night).	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor

Australian State & Link to authority responsible for driver licensing functions	LOG BOOK SYSTEM	Driving Instructor Usage
	Aged 25 or older doesn't need to fill out a log book or complete any minimum amount of supervised driving. **LOG BOOK:** Hours must be recorded in a paper log book or log book app. Exemptions to the 100 hours: Will need to prove that at least one of the following circumstances applies to you: No car available, No supervisor available. Limited access to a road network. Source>	No stipulation to use a professional driving instructor
WA: Department of Transport Western Australia	**AGE**: Under the age of **25** must complete a minimum of 50 hours of supervised driving experience (including at least 5 hours at night). Aged 25 or older doesn't need to fill out a log book or complete any minimum amount of supervised driving. **LOG BOOK:** Hours must be recorded in an app log book only. No paper log book. Exemptions: none sourced	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor No stipulation to use a professional driving instructor
SA: Department of Planning, Transport and Infrastructure South Australia	**AGE**: **Any age** must complete a minimum of 75 hours of supervised driving experience (including at least 15 hours at night). Any age required to fill out a log book or complete any minimum amount of supervised driving **LOG BOOK:** Hours must be recorded in a paper log book or log book app Exemptions: Exemption to hours of supervised driving may be granted if learner has driving experience from other states.	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor No stipulation to use a professional driving instructor
TAS: Department of State Growth Tasmania	At least 80 hours of supervised driving experience (including at least 15 hours at night). Two stages to learner Driving: **L1 Stage**: No log book required, Supervisory Driver required. **L2 Stage**: Includes Driving Assessment, then Supervisory Driver required, and completion of log book (no app log) Source>	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor No stipulation to use a professional driving instructor

Australian State & Link to authority responsible for driver licensing functions	LOG BOOK SYSTEM	Driving Instructor Usage
NT: Department of Transport Northern Territory	**AGE**: If under 25 years old need to hold provisional licence for at least two years before upgrading to a full licence. If you are 25 or older provisional licence needs to be held for at least one year. No minimum driving hours required. **LOG BOOK**: None required	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor No stipulation to use a professional driving instructor
ACT: Road Transport Authority Australian Capital Territory	**AGE**: Under the age of **25** must complete a minimum of 100 hours of supervised driving experience (including at least 10 hours at night). Aged 25 or older required to complete 50 supervised driving hours including 5 at night. **LOG BOOK:** Hours must be recorded in the paper log book only. There is no app log. Exemptions: none sourced	Anyone holding an appropriate licence can supervise/instruct the learning driver. Professional Driving Instructor For the first 10 hours, 3 hours of supervised driving hours will be applied for each singular hour driven whilst supervised by an ACT Accredited Driving Instructor.

Number of Lessons: Adults learning to drive with a left accelerator in auto car as a new driver

No research or statistics could be sourced indicating the number of lessons required for adults learning to drive with a left foot accelerator in auto car as a new driver.

Below is table summarizing the general requirements per state for adults learning to drive with a left accelerator in auto car.

Australian State & Link to information regarding the left accelerator requirement	Summary of requirement
NSW: Roads and Maritime Services New South Wales **Driving with a disability: Leg disabilities**	In an automatic vehicle, the accelerator and brake can be used by either the right or left leg, or both (one for each pedal). If you only use your left leg, the accelerator should be fitted to the left of the brake pedal (unless Roads and Maritime approves operation with the pedals in their normal position).
VIC: VicRoads **Guidelines for Occupational Therapy (OT) Driver Assessors.**	A person who has no functional use of their right foot or leg needs to use a left foot accelerator unless they can demonstrate appropriate control by use of prosthesis (if relevant). VicRoads will not test an applicant if the left foot is used to operate an accelerator fitted to the right of the brake pedal. Where an additional accelerator pedal is fitted to the left of the existing brake pedal, both the right and left accelerator pedal must be independently capable of being rendered inoperable.
QLD: Department of Transport and Main Roads	While there are no requirements which specifically cover the location of a left foot brake or accelerator pedal, attention should be paid to the

Australian State & Link to information regarding the left accelerator requirement	Summary of requirement
Queensland Code of Practice Vehicle Modifications Version 4.2 | February 2020	operator's needs. Due care should also be taken to ensure there is sufficient clearance from the brake pedal, to reduce the risk of the driver accidentally depressing the incorrect pedal. Where a vehicle is fitted with an additional accelerator pedal, the accelerator pedal not in use must be able to be: fitted with a cover; or, folded away; or disconnected/rendered inoperative.
WA: Department of Transport Western Australia	Not found
SA: Department of Planning, Transport and Infrastructure South Australia	Not found
TAS: Department of State Growth Tasmania	Not found
NT: Department of Transport Northern Territory	Not found
ACT: Road Transport Authority Australian Capital Territory	Not found

Number of Lessons: Adults re-learning to drive with a left accelerator in auto car (rather than a right one) as an existing driver

No research or statistics could be sourced indicating the number of lessons required for adults re-learning to drive with a left foot accelerator in auto car as an existing driver.

Number of Lessons: maximum number of driving lessons funded by other funding agencies

Other than a Victorian program funded by TAC, no evidence from other funding agencies could be found indicating a maximum number of driving lessons.

Traffic Accident Commission L2P Program

The TAC L2P Program is a state wide program funded by the TAC that matches young learner drivers with supervising driver mentors. The purpose of the program is to enable the learner driver to meet the mandated 120 hours of driving practice required to gain a probationary licence.

Participants are eligible for up to 7 professional driving lessons from a registered driving instructor. [3]

Funding learner driving lessons for other funding agencies

Traffic Accident commission TAC

TAC do not indicate the number of lessons or hours of instruction they will fund.

TAC pay the reasonable cost of a driving program, when recommended by an occupational therapist and overseen by a qualified driving instructor, in the following circumstances:

- The transport accident injury imposes physical, psychological or cognitive restrictions on your client, and
- Driving and participation will enable your client to commence, or return to, safe and competent driving.

TAC can pay for:

- driving instructor fees.
- lessons and training on how to use adaptations in modified vehicles.
- travel for a specialised driving instructor when:
  - your client with special needs requires a suitably modified vehicle, and
  - an instructor with the necessary skills and experience is not located near your client's home.

TAC will not pay for:

- driving lessons for your client if their driver's licence or learner permit is under suspension or has been cancelled for reasons which are not directly related to their transport accident injuries
- driving permit and licence fees
- driving programs that are not conducted safely
- driving programs conducted by an occupational therapist with no specialist training in driver assessment [4]

TAC Driving assessment (Instructor) services provided on or after 1 July 2020 [5]

Service Description	TAC Item Number	Maximum Payment Rate
Driving Assessment By Driving School - Driving Instructor Fees		
For 30 Minutes	ED0015*	$51.70
For 45 Minutes	ED0015*	$77.55
For 60 Minutes	ED0015*	$103.39
Pro-Rata For Longer Periods		

Department of Veteran Affairs (DVA)

No evidence could be found with regard to funding for learner driving lessons.

Lifetime Support Scheme

No specific evidence could be found regarding learner driving lessons other than an indication that the scheme "facilitated driving lessons and modifications to a vehicle" for a SCI participant [6], and that another participant is "is undergoing lessons to learn how to drive a modified vehicle". [7]

Cohorts

Although an extensive search was not carried out with regard to particular disability cohorts and driving education, there appears to be some research available in this area on learning methods, which may give insight into the number of hours/lesson requirements.

For example a study on learner drivers with cerebral palsy suggested a need for better methods for teaching CP learners search strategies, as problems increased for CP learners in those parts of training where high demands are set on visual search abilities. [8]

A 2017 study set out to explore the facilitators or barriers to driving education experienced by individuals with ASD or ADHD who obtained a learner's permit, from the perspective of the learner drivers and their driving instructors. It found that driving license theory was more challenging for individuals with ADHD, whilst individuals with ASD found translating theory into practice and adjusting to "unfamiliar" driving situations to be the greatest challenges. [9]

References

[1] Australian Driver Licensing. https://austroads.com.au/drivers-and-vehicles/registration-and-licensing/australian-driver-licensing. Accessed 9 July 2020. https://austroads.com.au/drivers-and-vehicles/registration-and-licensing/australian-driver-licensing

[2] The Centre for Accident Research & Road Safety Queensland(CARRS), How would changing driver training in the Queensland licensing system affect road safety?: Deliverable 3: Evidence-based driver education policy options, 2013, https://www.tmr.qld.gov.au/-/media/Safety/roadsafety/Road-safety-research-reports/report-3-evidence.pdf?la=en

[3] TAC. VicRoads and TAC Win Health Award for Learner Driver Mentor Program. http://www.tac.vic.gov.au/about-the-tac/media-and-events/news-and-events/2013-media-releases/vicroads-and-tac-win-health-award-for-learner-driver-mentor-program. Accessed 14 July 2020.

[4] TAC. Driving Instructor Guidelines. http://www.tac.vic.gov.au/providers/working-with-tac-clients/guidelines/provider-guidelines/driving-instructor-guideline. Accessed 14 July 2020.

[5] TAC. Driving Assessment (Instructor) Fees. http://www.tac.vic.gov.au/providers/invoicing-and-fees/fee-schedule/driving-assessment-instructor. Accessed 14 July 2020.

[6] Richard Davis | Lifetime Support Authority – South Australia. https://lifetimesupport.sa.gov.au/participants/participant-stories/richard-davis/. Accessed 15 July 2020.

[7] Peter Norde | Lifetime Support Authority – South Australia. https://lifetimesupport.sa.gov.au/participants/participant-stories/peter-norde/. Accessed 15 July 2020.

[8] Falkmer, Torbjörn, and Nils Petter Gregersen. "Fixation Patterns of Learner Drivers with and without Cerebral Palsy (CP) When Driving in Real Traffic Environments." Transportation Research Part F: Traffic Psychology and Behaviour, vol. 4, no. 3, Sept. 2001, pp. 171–85. ScienceDirect, https://www.sciencedirect.com/science/article/abs/pii/S1369847801000213

[9] "Experiences of Facilitators or Barriers in Driving Education from Learner and Novice Drivers with ADHD or ASD and Their Driving Instructors." Autism CRC, 29 July 2015, https://www.autismcrc.com.au/knowledge-centre/publications/experiences-facilitators-or-barriers-driving-education-learner-and

Research – Therapy Best Practice

Brief	In order to develop business rules for the funding of CB supports as part of the Participant Budget Model, we need the following information: • For the following disability groups: Parkinson's Disease, multiple sclerosis, muscular dystrophy, dementia, Huntington's Disease, arthritis, chronic fatigue, chronic pain, amputation. • What is considered best practice in terms of: a) The allied health team members of a multidisciplinary team, i.e. who should be involved in managing the disability? b) The frequency of intervention i.e. approximate dosage – how many hours per year is required for each professional? c) Evidence based practice for widely accepted therapy approaches. Not too much detail required, mainly eg "For MS, X therapy approach is often recommended, which involves intensive blocks of 20 sessions every X months". Looking for information again regarding number of hours that would be considered best practice.
Date	28/06/21
Requester(s)	Jane [redacted]- Assistant Director (TAB) Jean [redacted]- Senior Technical Advisor (TAB)
Researcher	Jane [redacted]- Research Team Leader (TAB)
Cleared	N/A

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The contents of this document are OFFICIAL

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2 Summary

- Information provided has been obtain from a rapid review of the literature. This includes best practice guidelines, systematic reviews from the Cochrane Collaboration and other high quality meta-analyses and reviews.
- The personal circumstances, goals of each individual, and severity of the disease impacts the level of intervention required. Therefore, it is often not possible to provide an exact number of hours required for each intervention. This is reflected in the literature as studies investigating the same intervention often deliver it at a different frequency, leading to a lack of agreement around gold standard levels.
- If the agency requires precise numbers around how many hours of intervention are useful per clinician they will need to commission systematic reviews of each type of intervention delivered, across various disease severities. This is a substantial tasks. Current literature

focuses on the effectiveness rather than the intensity of intervention. The level of intervention is often decided by the allied health professional looking after the patient.

3 Parkinson's disease

3.1 Clinician involved in management

A systematic review and meta-analysis of integrated care in Parkinson's disease provides a list of core team members to be included in interventions [1].

- Movement disorders specialist
- General neurologist
- PD specialist nurse
- Physiotherapist
- Occupational therapist
- Speech therapist
- Clinical psychologist
- Neuropsychologist
- Community mental health team
- Social worker
- Dietician

Models of care varied significantly, ranging from 4-8 weeks, 1-4 sessions a day (30 minutes to 2 hr per session) ranging from 1-7 days a week. No indication of what hours were allocated to each profession.

3.2 Best practice treatment and frequency of intervention

Recommendations for treatment are taken from the NICE UK guidelines [2].

1) First-line treatment
    a. Offer levodopa to people in the early stages of Parkinson's disease whose motor symptoms impact on their quality of life.
    b. Consider a choice of dopamine agonists, levodopa or monoamine oxidase B (MAO-B) inhibitors for people in the early stages of Parkinson's disease whose motor symptoms do not impact on their quality of life.

2) Non-pharmacological management
    a. Nurse specialist interventions
        i. Clinical monitoring and medicines adjustment.
        ii. A continuing point of contact for support, including home visits when appropriate.

iii. A reliable source of information about clinical and social matters of concern to people with Parkinson's disease and their family members and their carers (as appropriate).

b. Physiotherapy and physical activity [3]
   i. General physiotherapy: 4 weeks to 12 months. Only 2 studies reported duration of sessions which included 12 hrs over 4 weeks and 18 hrs over 6 weeks.
   ii. Exercise: Treatment sessions lasted from 30 minutes to two hours, and took place over a period of three to 24 weeks.
   iii. Treadmill: Treatment sessions lasted from 30 to 60 minutes, and took place over a period of four to eight weeks.
   iv. Cueing: Treatment sessions lasted from four to 30 minutes and took place over a period of a single session to 13 weeks.
   v. Dance: Dance classes lasted one hour over 12 to 13 weeks, with a trained instructor teaching participants the tango, waltz, or foxtrot.
   vi. Martial arts: Treatment lasted one hour and took place over a period of 12 to 24 weeks

c. Speech and language therapy [4]
   i. Median duration of therapy for those treated was four weeks with 68% attending a single weekly session, a further 22%, who were predominantly receiving Lee Silverman Voice Therapy (LSVT), had four or more therapy sessions per week. Most sessions (80%) lasted between 30-60 minutes.

d. Occupational therapy [5]
   i. A Cochrane Review from 2007 only found 2 studies that met inclusion criteria. These studies delivered intervention of 12 hours across 4 weeks, and 20 hours over 5 weeks.

e. Nutrition [6]
   i. Monitoring every four to six weeks if there have been any changes to medications or treatment plan, with particular focus on the swallowing recommendations.
   ii. Every three months if the patient's condition is stable.
   iii. For oral nutrition support, regular review of ONS prescriptions every three months is advisable, to ensure the appropriateness of the intervention.
   iv. Some centres offer one-day holistic reviews to re-assess mobility, swallow, speech and nutritional status.

* Dysphagia management should be conducted by speech and language therapists in conjunction with nurses and dietitians. No information provided on level/duration of intervention [7].

3) Deep brain stimulation
   a. Surgery is performed to implant a device that sends electrical signals to brain areas responsible for body movement. Electrodes are placed deep in the brain and are connected to a stimulator device.

4 Multiple sclerosis

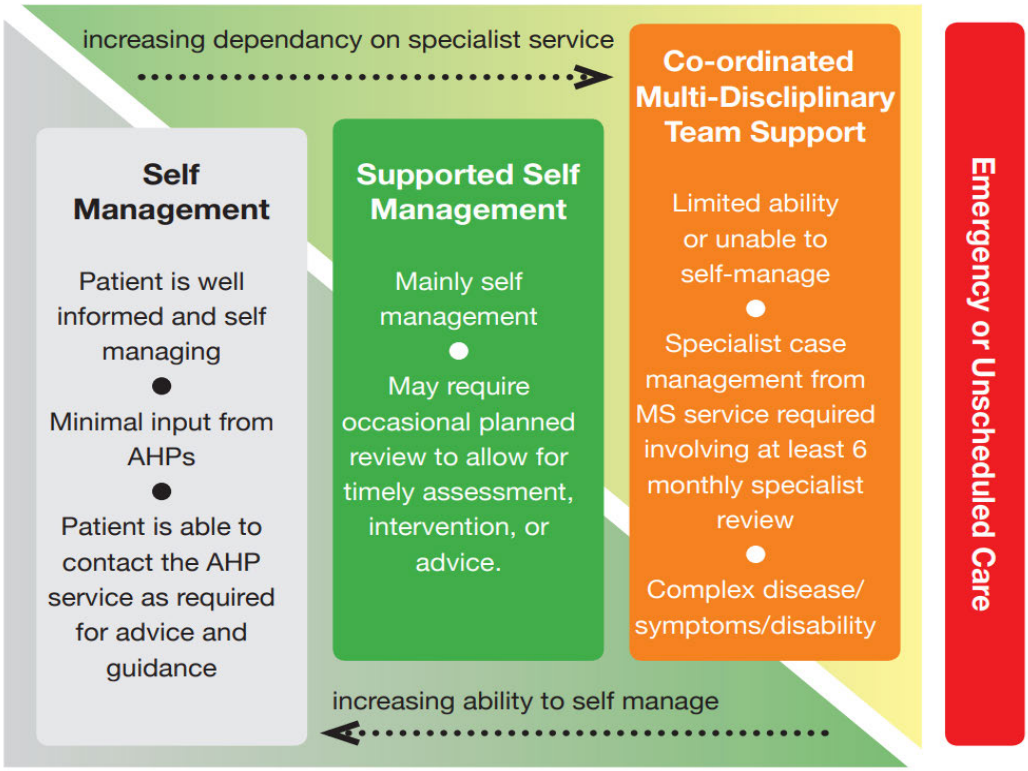
4.1 Clinician involved in management

There is variation in the make-up of MS multidisciplinary teams. The NICE MS Clinical Guideline states that: “As a minimum, the specialist neurological rehabilitation service should have as integral members of its team, specialist [8, 9]:

- Doctors (GPs, Neurologist)
- Nurses
- Physiotherapists
- Occupational therapists
- Speech and language therapists
- Dieticians
- Continence specialists
- Clinical psychologists
- Ophthalmologist/orthoptist
- Social workers.

General rehabilitation – patients must be seen for 6-8 sessions or for a 6-8 week period, however, appointments should be booked according to the needs of the patient [8]. The figure below describes the level of dependency on specialist services for varying levels of disease severity.

Figure 2[3]: Self Management/Specialist Service Dependency Model for People with MS



Patients are able to move fluidly in both directions between the different aspects of care illustrated, and such moves can be triggered either by the patient or their carer, or by the service professionals.

4.2 Best practice treatment and frequency of intervention

Determine how often the person with MS will need to be seen based on [9]:

- Their needs, and those of their family and carers
- The frequency of visits needed for different types of treatment (such as review of disease-modifying therapies, rehabilitation and symptom management).
    - *"Review information, support and social care needs regularly"*

The below interventions are listed in the NICE UK guidelines for the management of MS [9]

1) Exercise programs
2) Mindfulness-based training
3) Cognitive behavioural therapy
4) Fatigue management
5) Mobility rehabilitation
6) Spasticity management

7) Occupational therapy – memory or cognitive problems
8) Diet
9) Ocular rehab

A Cochrane Review of Multidisciplinary Rehabilitation (MD) for the treatment of MS has been conducted to determine its effectiveness [10]. The concept of MD comprises elements of physical therapy, occupational therapy, speech pathology, psychology and or neuropsychology, cognitive therapy and or behaviour management, social work, nutrition, orthotics, counselling input, recreation and vocational therapy.

Intensity of MD rehabilitation programme was subdivided into 'high' or 'low' intensity

- High intensity therapy involved input from at least two disciplines, a minimum of thirty minutes per session and total duration of at least 2-3 hours of interrupted therapy per day for at least 4 days per week. This is usually provided in inpatient settings and some outpatient programmes.
- Low intensity programmes varied, the intensity and duration of therapy was lesser than that provided in inpatient rehabilitation settings and was dependent upon the type of rehabilitation setting and available resources

From this review, it has not been possible to suggest best 'dose' of therapy, further studies are needed to suggest optimum number, duration and intensity of treatment sessions.

Neuropsychological rehabilitation

A Cochrane Review of neuropsychological rehabilitation (delivered by psychologists) for MS was conducted in 2014 [11]. It found that the number of intervention sessions varied from eight to 36, the duration of the rehabilitation intervention from four weeks to six months, and the frequency from two times per month to five times per week. When analysing the results with regard to the number of sessions, duration and frequency, no definite conclusions can be drawn about the effect of these factors on rehabilitation outcomes.

Exercise

Ranging from 6 to 24 weeks in duration, ranging from once to 5 times weekly frequency [12].

5 Muscular dystrophy

5.1 Clinician involved in management

Muscular dystrophy (MD) is a group of diseases that cause progressive weakness and loss of muscle mass. The most common form of MD is Duchenne's MD which most commonly occurs in young boys. The below will be presented for Duchenne's MD.

The care team should include a [13]:

- Neurologist with expertise in neuromuscular diseases
- Physical medicine and rehabilitation specialist

- Physiotherapist
- Occupational therapists.
- Speech-language pathologists
- Orthotist
- Psychologist
- Dietician.

Some people might also need a lung specialist (pulmonologist), a heart specialist (cardiologist, a sleep specialist, a specialist in the endocrine system (endocrinologist), an orthopedic surgeon and other specialists.

5.2 Best practice treatment and frequency of intervention

Several types of therapy and assistive devices can improve the quality and sometimes the length of life in people who have muscular dystrophy. Examples include [13]:

- **Range-of-motion and stretching exercises.** Muscular dystrophy can restrict the flexibility and mobility of joints. Limbs often draw inward and become fixed in that position. Range-of-motion exercises can help to keep joints as flexible as possible.
- **Exercise.** Low-impact aerobic exercise, such as walking and swimming, can help maintain strength, mobility and general health. Some types of strengthening exercises also might be helpful.
    - Optimal exercise modality and intensity of exercise for people with a muscle disease is still unclear. Large variation in frequency, duration and intensity exists within the literature [14-16].
- **Braces.** Braces can help keep muscles and tendons stretched and flexible, slowing the progression of contractures. Braces can also aid mobility and function by providing support for weakened muscles.
- **Mobility aids.** Canes, walkers and wheelchairs can help maintain mobility and independence.
- **Psychosocial intervention**
- **Gastrointestinal and nutritional management**

Guidelines published for the diagnosis and management of Duchenne's MD essentially states that patients should be assessed/reviewed every 6 months by allied health professionals involved in their multidisciplinary care [17].

There is no specific guidance on how many hours/visits are required for each rehabilitation intervention or clinician.

"Provide direct treatment by physical and occupational therapists, and speech-language pathologists, based on assessments and individualised to the patient."

The above also goes for psychological assessment and intervention. The number of visits will depend on the patient's current needs and ability to cope with their diagnosis.

6 Dementia

6.1 Clinician involved in management

The needs of people with dementia vary widely and tailoring care to each person's circumstances can be complex. A multidisciplinary approach in which different health professionals work together is important [18].

A medical specialist is required to make a dementia diagnosis. These include:

- General physicians
- General practitioners
- Geriatricians
- Neurologists
- Psychiatrists
- Rehabilitation physicians

A number of different allied health professionals may be required at different points in time, including but not limited to [19]:

- Audiologists
- Dentists
- Dietitians
- Occupational therapists
- Orthoptists
- Physiotherapists
- Podiatrists
- Psychologists
- Social workers
- Speech pathologists

Nurses and aged care workers are also involved in the care of patients with dementia.

6.2 Best practice treatment and frequency of intervention

Best practice care has been taken from the UK NICE guidelines on dementia [20]:

1) Person centred care
    a. Involving people in decision making
    b. Providing information
    c. Advance care planning
2) Care coordination
    a. Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care.
3) Interventions to promote cognition, independence and wellbeing

a. "Offer a range of activities to promote wellbeing that are tailored to the person's preferences" – i.e. previous hobbies/interests
b. Cognitive Stimulation for mild to moderate dementia
    i. Cochrane Review found that intervention ranged from 4 weeks to 24 months [21]. Median session length across the studies was 45 minutes, and the median frequency was three times a week, ranging from one to five times a week. The total possible exposure to the intervention varied dramatically, from 10 to 12 hours to 375 hours in the two-year study. Across the 15 studies, the median exposure time was 30 hours.
c. Group reminiscence therapy for mild to moderate dementia
    i. Cochrane Review concluded that duration and frequency of the sessions could differed. Sessions ranged from 2-8 times at either 1-2 hours (face to face or telephone) and were delivered by occupational therapists, trained recreation therapists [22].
d. Cognitive rehabilitation or occupational therapy for mild to moderate dementia
    i. A Cochrane Review found that intervention duration ranged from 2 to 104 weeks. Sessions ranged from 1-12 per week. More intense was classified as more than 3 formal sessions per week. Duration was 30 to 240 minutes. Those in day care facilities were often longer [23].

NOTE: The Cochrane Collaboration have undertaken various reviews of non-pharmacological interventions for dementia and found that many lack convincing evidence or well described treatment protocols. These include homeopathy, acupuncture, aromatherapy, snoezelen, validation therapy or dance movement therapy.

There is promising evidence that exercise programs may improve the ability to perform ADLs in people with dementia, although some caution is advised in interpreting these findings. Included studies were highly heterogeneous in terms of subtype and severity of participants' dementia, and type, duration, and frequency of exercise [24].

4) Pharmacological interventions
    a. acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine as monotherapies are recommended as options for managing mild to moderate disease
5) Caregiver education and skills training
    a. A meta-analysis of 23 randomized clinical trials provides strong confirmation of the benefits of caregiver education and skills training interventions for reducing behavioural symptoms [19]. Collectively, these trials involved 3,279 community-dwelling caregivers and patients. Effective interventions were wide-ranging and included caregiver education, skills training (problem solving, communication strategies), social support (linking caregivers to others), and/or environmental modifications (assistive device use, creating a quiet uncluttered space). Interventions varied in dose, intensity, and delivery mode (telephone, mail, face-to-face, groups, computer technologies.
    b. Successful interventions identified included approximately **nine to 12 sessions** tailored to the needs of the person with dementia and the caregiver and were

delivered individually in the home using multiple components **over 3–6 months** with periodic follow-up [19].

While pharmacological intervention can be conveniently packaged and standardised, with a measured dose, non-pharmacological interventions can be more difficult to evaluate [25]. The same intervention may be used in different studies, but it may comprise quite different components [25]. Non-pharmacological interventions have rarely used a standardised treatment manual; mainly due to the range of individual differences between people with dementia [25].

Although some interventions can be offered for a discrete period of time, such as half an hour per day, many others involve intervention at the level of the care setting or in the general approach or interactive style of those providing care (i.e. depends on disease severity, level or care and care providers) [25].

Frequency of intervention is briefly mentioned in the Australian Clinical Practice Guidelines and Principles of Care for People with Dementia [18]. Statements include:

- *Health system planners should ensure that people with dementia have access to a care coordinator who can work with them and their carer's and families from the time of diagnosis. If more than one service is involved in the person's care, services should agree on one provider as the person's main contact, who is responsible for coordinating care across services at* ***whatever intensity is required****.*
- A care plan developed in partnership with the person and his or her carer(s) and family that ***takes into account the changing needs of the person.***
- ***Formal reviews of the care plan at a frequency agreed between professionals involved*** *and the person with dementia and/or their carer(s) and family.*

7 Huntington's disease

7.1 Clinician involved in management

The multidisciplinary team assesses the stage of the disease and formulates, coordinates and implements the individual care and treatment plan and consists of [26]:

- Physician
- Psychologist
- Speech and language therapist
- Social worker
- Occupational therapist
- Case manager
- Psychologist
- Dentist/oral health specialist

7.2 Best practice treatment and frequency of intervention

Only non-pharmacological recommendations will be presented [27].

Motor Disorders

- Chorea
  - Mouth guards splints.
  - Physiotherapy, OT, speech intervention to assess protective measures.
- Dystonia
  - Active and passive rehabilitation with a physiotherapist to maintain range of movement.
- Rigidity
  - Physiotherapy is recommended to improve or maintain mobility and prevent the development of contractures and joint deformity.
- Swallowing disorders
  - Motor skills training with speech therapist.
  - Psychology for mood, behaviour, emotional status and cognition
  - Provision of information and advice by a dietician, on food textures and consistency and food modifications, bolus size and placement, safe swallowing procedures, elimination of distractions and on focusing attention on just one task at a time can help to avoid aspirations and leads to improvement of swallowing disorders.
- Gait and balance disorders
  - Rehabilitative methods (e.g. physiotherapy and occupational therapy) may improve walking and balance disorders and prevent from their main complications (falls, fractures, loss of autonomy). Interventions for gait and balance should start as early as possible and be continued and adapted throughout the progression of the disease.
  - Supervised low impact exercise.
- Manual dexterity
  - Management with physiotherapy and occupational therapy may be useful to reduce the functional impact of fine motor skill deterioration.
  - OT may suggest adaptive aids to compensate for the deterioration of manual dexterity (adapted cutlery, computer keyboard, adapted telephone, etc.)
- Global motor capacities
  - Referral to a physiotherapist is recommended in order to facilitate the development of a therapeutic relationship, promote sustainable exercise behaviours and ensure long-term functional independence. Exercise programs should be personalized (considering abilities and exercise capacity), goal directed and task specific.
- Cognition
  - Multiple rehabilitation strategies (speech therapy, occupational therapy, cognitive and psychomotricity) might improve or stabilise transitorily cognitive functions (executive functions, memory, language...) at some point of time in the course of the disease.
  - Cognitive stimulation
- Language and communication disorders
  - Communication disorders in HD are variable, requires comprehensive assessment of language and of other factors such as mood, motivation and behaviour.

- Multi-disciplinary input such as Speech & Language Therapy and Physiotherapy help to retain communication and social interaction
- The changing communication needs of the person with HD will be monitored and reassessed throughout the course of the disease to plan effective management strategies at all stages.

- Psychiatric disorders
  - Based on data from other neurodegenerative conditions, mindfulness-based cognitive therapy and Acceptance and Commitment Therapy may be useful.
  - Underlying triggers causing changes in mood or behaviour should be addressed.
  - The duration of treatment is generally for over 6 months and can be for several years

*Unable to find precise data on frequency or duration of interventions for each professional.

8 Arthritis

The main treatment for arthritis is Methotrexate.

The NICE UK guidelines provides the below recommendations [28].

Non-pharmacological management

- Physiotherapy
  - Adults with RA should have access to specialist physiotherapy, with periodic review
  - Improve general fitness and encourage regular exercise
    - 3 to 6 face to face sessions over 3-6 month period [29].
  - Learn exercises for enhancing joint flexibility, muscle strength and managing other functional impairments
  - Learn about the short-term pain relief provided by methods such as transcutaneous electrical nerve stimulators (TENS) and wax baths.
- Occupational therapy
  - Adults with RA should have access to specialist occupational therapy, with periodic review if they have:
    - Difficulties with any of their everyday activities, or
    - Problems with hand function.
- Hand exercise programmes
  - Consider a tailored strengthening and stretching hand exercise programme for adults with RA with pain and dysfunction of the hands or wrists if:
    - They are not on a drug regimen for RA, or
    - They have been on a stable drug regimen for RA for at least 3 months.

The tailored hand exercise programme for adults with RA should be delivered by a practitioner with training and skills in this area.

- Podiatry
  - All adults with RA and foot problems should have access to a podiatrist for assessment and periodic review of their foot health needs.

- Functional insoles and therapeutic footwear should be available for all adults with RA if indicated.

- Psychological interventions
  - Offer psychological interventions (for example, relaxation, stress management and cognitive coping skills [such as managing negative thinking]) to help adults with RA adjust to living with their condition.
  - Meta-analysis of psychological interventions for arthritis pain found that interventions tested were most commonly delivered in a total of nine sessions of 85 min duration, offered on a weekly or biweekly basis [30].
- Diet and complementary therapies
  - Inform adults with RA who wish to experiment with their diet that there is no strong evidence that their arthritis will benefit. However, they could be encouraged to follow the principles of a Mediterranean diet (more bread, fruit, vegetables and fish; less meat; and replace butter and cheese with products based on vegetable and plant oils).
  - Inform adults with RA who wish to try complementary therapies that although some may provide short-term symptomatic benefit, there is little or no evidence for their long-term efficacy.
  - If an adult with RA decides to try complementary therapies, advise them: these approaches should not replace conventional treatment.

Monitoring

Ensure that all adults with RA have:

- Rapid access to specialist care for flares
- Information about when and how to access specialist care, and
- Ongoing drug monitoring.

Consider a review appointment to take place **6 months** after achieving treatment target (remission or low disease activity) to ensure that the target has been maintained.

Offer all adults with RA, including those who have achieved the treatment target, an annual review to:

  - Assess disease activity and damage, and
  - Measure functional ability (using, for example, the Health Assessment Questionnaire [HAQ]).
  - Check for the development of comorbidities, such as hypertension, ischaemic heart disease, osteoporosis and depression.
  - Assess symptoms that suggest complications, such as vasculitis and disease of the cervical spine, lung or eyes.
  - Organise appropriate cross referral within the multidisciplinary team.

9 Chronic fatigue syndrome

9.1 Clinician involved in management

In most cases, a GP should be able to diagnose chronic fatigue syndrome (CFS). However, if, after a careful history, examination and screening investigations, the diagnosis remains uncertain, the opinion of a specialist physician, adolescent physician or paediatrician should be sought [31].

Other non-medical professionals include:

- Physiotherapists
- Occupational therapists
- Psychologists
- Social workers
- Dieticians

9.2 Best practice treatment and frequency of intervention

Care should be provided to people with CFS using a coordinated multidisciplinary approach. Based on the person's needs, include health and social care professionals with expertise in the following [31, 32]:

- self-management strategies, including energy management
- symptom management
- managing flares and relapse
- activities of daily living
- emotional wellbeing, including family and sexual relationships
- diet and nutrition
- mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services
- social care and support
- support to engage in work, education, social activities and hobbies

No detailed information could be sourced around how many hours are required per clinician for each of these approaches. It is clearly stated that service providers should be "adapting the timing, length and frequency of all appointments to the person's needs" [32].

There is still little evidence to support any particular management or intervention for CFS in primary care that can provide an effective early intervention [33]. The only two evidence based therapies recommended by NICE are:

- Cognitive Behavioural Therapy
    - Five to 16 sessions. Sessions ranged from 30 minutes to 150 minutes [34]
    - People with CFS should not undertake a physical activity or exercise programme unless it is delivered or overseen by a physiotherapist or occupational therapist who has training and expertise in CFS [32].
    -

- Exercise Therapy
    - Duration of the exercise therapy regimen varied from 12 weeks to 26 weeks
    - three and five times per week, with a target duration of 5 to 15 minutes per session using different means of incrementation, often exercise at home [35]

10 Chronic pain

This is a very broad area. Treatments depend on location of pain. Musculoskeletal pain, particularly related to joints and the back, is the most common single type of chronic pain.

Information provided in the section on arthritis directly relates to the management of chronic pain.

A substantial systematic review by Skelly, Chou [36] investigated non-pharmacological interventions for chronic pain. Interventions that improved function and/or pain for ≥1 month included:

- Low back pain:
    - Exercise
    - Psychological therapy
    - Spinal manipulation
    - Low-level laser therapy
    - Massage
    - Mindfulness-based stress reduction
    - Yoga
    - Acupuncture
    - Multidisciplinary rehabilitation
- Neck pain
    - Exercise
    - Low-level laser
    - Mind-body practices
    - Massage
    - Acupuncture
- Knee osteoarthritis
    - Exercise
    - CBT
- Hip osteoarthritis
    - Exercise
    - Manual therapies
- Fibromyalgia
    - Exercise
    - CBT
    - Myofascial release massage
    - Mindfulness practices
    - Acupuncture

Substantial variability in the numbers of sessions, length of sessions, duration of treatment, methods of delivering the interventions and the experience and training of those providing the interventions present a challenge to assessing applicability [36].

The range and duration of sessions of interventions are provided below.

- Psychological therapy sessions ranged from six to eight, and the duration of therapy ranged from 6 to 8 weeks
- Exercise therapy ranged from 6 weeks to 12 months, and the number of supervised exercise sessions ranged from 3 to 52.
- Ultrasound therapy was 4 and 8 weeks and the number of sessions was 6 and 10.
- Laser therapy ranged from 2 to 6 weeks and the number of sessions ranged from 10 to 12.
- Manipulation therapy sessions ranged from 4 to 24 and the duration of therapy ranged from 4 to 12 weeks.
- Massage therapy ranged from 2 to 10 weeks and the number of massage sessions ranged from 4 to 24
- Mindfulness based stress reduction 1.5 to 2 hour weekly group sessions for 8 weeks.
- Yoga therapy ranged from 4 to 24 weeks and the number of sessions ranged from 4 to 48.
- Acupuncture therapy ranged from 6 to 12 weeks and the number of acupuncture sessions ranged from 6 to 15.
- Relaxation training and muscle performance exercise therapy were done in 30-minute sessions three times per week for 12 weeks,

11 Amputation

11.1 Clinician involved in management

The Limbs 4 Life is the peak body for amputees in Australia. They provide a list of professionals who assist with rehabilitation of amputees [37].

- Rehabilitation Consultant (doctor)
  - Oversees and coordinates medical care.
- Occupational Therapist
  - Helps adjust to day to day activities like: personal care, domestic tasks such as: meal preparation, accessing your place of residence, driving, education or work readiness. If you are an upper limb amputee the occupational therapist will assist you to set goals, teach you how to perform tasks, explore modifications required to achieve goals (e.g. changes within the home or workplace), explore equipment to assist with completing tasks and assist you with the functional training of your prosthesis.
- Physiotherapist
  - Design a tailored exercise program tailored. They will assist with balance, flexibility, strength and stamina. They will help with mobility aids such as: wheelchairs, walking frames, crutches and other assistive devices.
- Prosthetist

- Will look after the design, manufacture, supply and fit of the prosthesis. Together, you will discuss and decide on the prosthetic components to suit your needs and lifestyle.

- Psychologist
  - Supports individuals and fosters positive mental health outcomes and personal growth.
- Nursing team
  - Assists with your medications, personal hygiene, bathing and dressing and any wound care and diabetic management that is required.
- Dietitian
- Podiatrist

11.2 Best practice treatment and frequency of intervention

Physiotherapy
The physiotherapist progresses the patient through a programme based on continuous assessment and evaluation [38]. Through regular assessment, the physiotherapist should identify when the individual has achieved optimum function with a prosthesis, facilitating discharge to a maintenance programme.

The consensus opinion is that the physiotherapist should contribute to the management of wounds, scars, residual limb pain and phantom pain and sensation together with other members of the multidisciplinary team [38].

During prosthetic rehabilitation *patients should receive physiotherapy as often as their needs and circumstances dictate* [38].

Occupational therapy

The occupational therapy practitioner provides critical interventions, such as [39]"

- identifying the client's functional goals, which can include self-care, home management, work tasks, driving, child care, and leisure activities, and offering modifications to complete these goals if required
- analysing tasks and providing modifications to achieve functional goals
- providing education on compensatory techniques and equipment to accomplish tasks and activities
- providing prosthetic training
- identifying and addressing psychosocial issues

Occupational therapy intervention will vary according to individual needs, and phases of intervention may overlap, depending on the person's progress [39].

The administration of interventions for phantom limb have been shown to range between one day and 12 weeks, with one to five sessions per week [40] .

Psychology

Counselling and psychological support is available to the person and their valued others preoperatively and continues as part of lifelong management [41].

Experienced clinical counselling and psychological support should be available to assist with issues such as adjustment and pain management from the acute phase, and throughout lifelong management [41].

Psychosocial issues are evaluated and addressed as part of the overall treatment plan and reviewed regularly throughout the care journey [41].

No information could be sourced about how many sessions are required.

12 References

1. Rajan R, Brennan L, Bloem BR, Dahodwala N, Gardner J, Goldman JG, et al. Integrated Care in Parkinson's Disease: A Systematic Review and Meta-Analysis. Movement Disorders [Internet]. 2020 2020/09/01; 35(9):[1509-31 pp.]. Available from: https://doi.org/10.1002/mds.28097.
2. National Institute for Health and Care Excellence (NICE). Parkinson's disease in adults. 2017. Available from: https://www.nice.org.uk/guidance/ng71/resources/parkinsons-disease-in-adults-pdf-1837629189061.

3. Tomlinson CL, Patel S, Meek C, Herd CP, Clarke CE, Stowe R, et al. Physiotherapy versus placebo or no intervention in Parkinson's disease. Cochrane Database of Systematic Reviews [Internet]. 2013; (9). Available from: https://doi.org//10.1002/14651858.CD002817.pub4.
4. Herd CP, Tomlinson CL, Deane KHO, Brady MC, Smith CH, Sackley CM, et al. Speech and language therapy versus placebo or no intervention for speech problems in Parkinson's disease. Cochrane Database of Systematic Reviews [Internet]. 2012; (8). Available from: https://doi.org//10.1002/14651858.CD002812.pub2.
5. Dixon L, Duncan DC, Johnson P, Kirkby L, O'Connell H, Taylor HJ, et al. Occupational therapy for patients with Parkinson's disease. Cochrane Database of Systematic Reviews [Internet]. 2007; (3). Available from: https://doi.org//10.1002/14651858.CD002813.pub2.
6. The Association of UK Dieticians. Best practice guidance for dietitians on the nutritional management of Parkinson's. 2021. Available from: https://www.parkinsons.org.uk/sites/default/files/2021-02/Best%20practice%20guidance%20for%20dietitians%20on%20the%20nutritional%20management%20of%20Parkinson%27s%20FINAL.pdf.

7. Deane K, Whurr R, Clarke CE, Playford ED, Ben-Shlomo Y. Non-pharmacological therapies for dysphagia in Parkinson's disease. Cochrane Database of Systematic Reviews [Internet]. 2001; (1). Available from: https://doi.org//10.1002/14651858.CD002816.
8. Dix K, Green H. Defining the value of Allied Health Professionals with expertise in Multiple Sclerosis. 2013. Available from: https://support.mstrust.org.uk/file/defining-the-value-AHPs.pdf.

9. (NICE) NIfHaCE. Multiple sclerosis in adults: management. 2019. Available from: https://www.nice.org.uk/guidance/cg186/resources/multiple-sclerosis-in-adults-management-pdf-35109816059077.

10. Khan F, Turner-Stokes L, Ng L, Kilpatrick T, Amatya B. Multidisciplinary rehabilitation for adults with multiple sclerosis. Cochrane Database of Systematic Reviews [Internet]. 2007; (2). Available from: https://doi.org//10.1002/14651858.CD006036.pub2.
11. Rosti-Otajärvi EM, Hämäläinen PI. Neuropsychological rehabilitation for multiple sclerosis. Cochrane Database of Systematic Reviews [Internet]. 2014; (2). Available from: https://doi.org//10.1002/14651858.CD009131.pub3.

12. Hayes S, Galvin R, Kennedy C, Finlayson M, McGuigan C, Walsh CD, et al. Interventions for preventing falls in people with multiple sclerosis. Cochrane Database of Systematic Reviews [Internet]. 2019; (11). Available from: https://doi.org//10.1002/14651858.CD012475.pub2.
13. Mayo Foundation for Medical Education and Research. Muscular Dystrophy 2021 [Available from: https://www.mayoclinic.org/diseases-conditions/muscular-dystrophy/symptoms-causes/syc-20375388.
14. Voet NBM, van der Kooi EL, van Engelen BGM, Geurts ACH. Strength training and aerobic exercise training for muscle disease. Cochrane Database of Systematic Reviews [Internet]. 2019; (12). Available from: https://doi.org//10.1002/14651858.CD003907.pub5.
15. Birnkrant DJ, Bushby K, Bann CM, Alman BA, Apkon SD, Blackwell A, et al. Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. The Lancet Neurology [Internet]. 2018 2018/04/01/; 17(4):[347-61 pp.]. Available from: https://www.sciencedirect.com/science/article/pii/S1474442218300255.
16. Birnkrant DJ, Bushby K, Bann CM, Apkon SD, Blackwell A, Colvin MK, et al. Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. The Lancet Neurology [Internet]. 2018 2018/05/01/; 17(5):[445-55 pp.]. Available from: https://www.sciencedirect.com/science/article/pii/S1474442218300267.
17. Birnkrant DJ, Bushby K, Bann CM, Apkon SD, Blackwell A, Brumbaugh D, et al. Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. The Lancet Neurology [Internet]. 2018 2018/03/01/; 17(3):[251-67 pp.]. Available from: https://www.sciencedirect.com/science/article/pii/S1474442218300243.
18. Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney: Guideline Adaptation Committee; 2016. Available from: https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf.

19. Brodaty H, Arasaratnam C. Meta-Analysis of Nonpharmacological Interventions for Neuropsychiatric Symptoms of Dementia. American Journal of Psychiatry [Internet]. 2012 2012/09/01; 169(9):[946-53 pp.]. Available from: https://doi.org/10.1176/appi.ajp.2012.11101529.
20. National Institute for Health Care Excellence. National Institute for Health and Care Excellence: Clinical Guidelines. Dementia: Assessment, management and support for people living with dementia and their carers. London: National Institute for Health and Care Excellence (UK)

Copyright © NICE 2018.; 2018.
21. Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. Cochrane Database of Systematic Reviews [Internet]. 2012; (2). Available from: https://doi.org//10.1002/14651858.CD005562.pub2.
22. Möhler R, Renom A, Renom H, Meyer G. Personally tailored activities for improving psychosocial outcomes for people with dementia in community settings. Cochrane Database of Systematic Reviews [Internet]. 2020; (8). Available from: https://doi.org//10.1002/14651858.CD010515.pub2.
23. Bahar-Fuchs A, Martyr A, Goh AMY, Sabates J, Clare L. Cognitive training for people with mild to moderate dementia. Cochrane Database of Systematic Reviews. 2019(3).
24. Forbes D, Forbes SC, Blake CM, Thiessen EJ, Forbes S. Exercise programs for people with dementia. Cochrane Database of Systematic Reviews [Internet]. 2015; (4). Available from: https://doi.org//10.1002/14651858.CD006489.pub4.

25. National Collaborating Centre for Mental Health. Dementia: A NICE-SCIE guideline on supporting people with dementia and their carers in health and social care: British Psychological Society; 2007. Dementia. 2014.
26. Veenhuizen RB, Kootstra B, Vink W, Posthumus J, van Bekkum P, Zijlstra M, et al. Coordinated multidisciplinary care for ambulatory Huntington's disease patients. Evaluation of 18 months of implementation. Orphanet J Rare Dis [Internet]. 2011; 6:[77- pp.]. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3253686/.
27. Bachoud-Lévi A-C, Ferreira J, Massart R, Youssov K, Rosser A, Busse M, et al. International Guidelines for the Treatment of Huntington's Disease. Frontiers in Neurology [Internet]. 2019 2019-July-03; 10(710). Available from: https://www.frontiersin.org/article/10.3389/fneur.2019.00710.
28. National Institute for Health and Care Excellence (NICE). Rheumatoid arthritis in adults: management. 2018.
29. Peter WF, Swart NM, Meerhoff GA, Vliet Vlieland TPM. Clinical Practice Guideline for Physical Therapist Management of People With Rheumatoid Arthritis. Physical Therapy [Internet]. 2021. Available from: https://doi.org/10.1093/ptj/pzab127.
30. Dixon KE, Keefe FJ, Scipio CD, Perri LM, Abernethy AP. Psychological interventions for arthritis pain management in adults: A meta-analysis. Health Psychology [Internet]. 2007; 26(3):[241-50 pp.].
31. Working Group of the Royal Australasian College of Physicians. Chronic fatigue syndrome. Clinical practice guidelines--2002. Med J Aust [Internet]. 2002 May 6; 176(S9):[S17-s55 pp.].
32. National Institute for Health and Care Excellence (NICE). Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management. 2020. Available from: https://www.nice.org.uk/guidance/gid-ng10091/documents/draft-guideline.

33. Hughes JL. Chronic Fatigue Syndrome and Occupational Disruption in Primary Care: Is There a Role for Occupational Therapy? British Journal of Occupational Therapy [Internet]. 2009 2009/01/01; 72(1):[2-10 pp.]. Available from: https://doi.org/10.1177/030802260907200102.
34. Price JR, Mitchell E, Tidy E, Hunot V. Cognitive behaviour therapy for chronic fatigue syndrome in adults. Cochrane Database of Systematic Reviews [Internet]. 2008; (3). Available from: https://doi.org//10.1002/14651858.CD001027.pub2.
35. Larun L, Brurberg KG, Odgaard-Jensen J, Price JR. Exercise therapy for chronic fatigue syndrome. Cochrane Database of Systematic Reviews [Internet]. 2019; (10). Available from: https://doi.org//10.1002/14651858.CD003200.pub8.
36. Skelly AC, Chou R, Dettori JR, Turner JA, Friedly JL, Rundell SD, et al. Agency for Healthcare Research and Quality: Comparative Effectiveness Reviews. 2020. In: Noninvasive Nonpharmacological Treatment for Chronic Pain: A Systematic Review Update [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US). Available from: https://www.ncbi.nlm.nih.gov/books/NBK556229/.
37. Limbs 4 Life. Your recovery 2021 [Available from: https://www.limbs4life.org.au/steps-to-recovery/your-rehabilitation-team.
38. Broomhead P, Dawes D, Hale C, Lambert A, Quinlivan D, Shepherd R. Evidence based clinical guidelines for the physiotherapy management of adults with lower limb prostheses. British Association of Chartered Physiotherapists in Amputation Rehabilitation; 2003. Available from: https://docuri.com/download/csp-guideline-bacpar_59c1cb4df581710b2860eb11_pdf.

39. Gulick K. The occupational therapy role in rehabilitation for the person with an upper-limb amputation. American Occupational Therapy Association [Internet]. 2007. Available from:

https://www.aota.org/About-Occupational-Therapy/Professionals/RDP/upper-limb-amputation.aspx.

40. Othman R, Mani R, Krishnamurthy I, Jayakaran P. Non-pharmacological management of phantom limb pain in lower limb amputation: a systematic review. Physical Therapy Reviews [Internet]. 2018 2018/03/04; 23(2):[88-98 pp.]. Available from: https://doi.org/10.1080/10833196.2017.1412789.

41. Innovation AfC. ACI Care of the Person following Amputation: Minimum Standards of Care. Australia; 2017. Available from: https://aci.health.nsw.gov.au/__data/assets/pdf_file/0019/360532/The-care-of-the-person-following-amputation-minimum-standards-of-care.pdf.

Specialised driving lessons

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The Research Team are unable to ensure that the information listed below provides an accurate & up-to-date snapshot of these matters

Research question: 1. How many hours of specialised driving lessons is generally required for an individual with a disability to learn how to drive and attain their driver's license? How does this vary between disability populations (e.g. ABI, Stroke, ID, ASD)?

2. What is the best practice approach for a driver rehabilitation program, are there any guidelines regarding the frequency of driving lessons and frequency of Driver Trained Occupational Therapist review/re-assessment?

3. What are the factors which determine successful attainment of licensing, especially for individuals with cognitive impairments?

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2. Summary

This paper focussed on on-road driver training interventions for people with cognitive or emotional concerns which impact their driving. There is very little evidence evaluating on-road driving lessons despite this being one of the most widespread interventions used for driver training and rehabilitation. Lack of evidence for on-road driving lessons is a known issue for researchers and driver trained occupational therapists (DTOTs) and is frequently remarked on in the research literature.

Relevant studies have been conducted for drivers with Autism Spectrum Disorder (ASD) and traumatic brain injury (TBI). Surveys of driving instructors suggest learners with ASD may require 20-40 formal driving lessons. Evidence shows that while most people with TBI can return to driving, those who require additional training need on average seven 2hr formal driving lessons. Researchers have explored for other cohorts (stroke, mild cognitive impairment, psychosocial disability) but available studies were either exploratory (e.g., describing driver profiles) or examined other interventions (e.g., simulator training, driver education, physical rehabilitation etc.).

While there is consistent evidence that suggests people with disability take longer to get their license, any quantified results are based on very few studies and should be treated with caution.

No guidelines were found which offered recommendations for duration, frequency or number of driving lessons for people with cognitive or emotional concerns that might impact their driving. In response to lack of evidence, guidelines stress the need for individualised interventions which account for the learners' specific needs.

3. Guidelines

Database searches uncovered no published guidelines recommending an overall approach to frequency or duration of specialised driving lessons, reviews or reassessments for people with cognitive or emotional concerns that might impact their driving.

Assessing fitness to drive is a collaboration of AustRoads and the National Transport Commission and provides guidelines for determining when a driver with some medically relevant impairment meets licensing requirements (AustRoads & National Transport Commission, 2022). This includes required frequency of reassessment after a person has obtained their license. For example, reassessment may be more frequent if a driver has a progressive condition. However, *Assessing fitness to drive* does not provide recommendations around frequency of reassessment for drivers prior to obtaining their license. Nor does it provide guidelines around frequency or duration of lessons or rehabilitation strategy for drivers wanting to gain or regain their license. In fact, the guidelines state explicitly, "there is currently limited evidence to support the use of particular rehabilitation or retraining strategies" (AustRoads & National Transport Commission, 2022, p.23).

VicRoad's *Guidelines for Occupational Therapy Driver Assessors* (VicRoads) does include some recommendations around driving lessons. VicRoads says, for instance, that driving instructors need to "use appropriate training methods to accommodate the driver's past experience, current skill level and communication/impairment needs" (p.33). This might involve specifying number of lessons or recommending a duration of lessons. However, the guidelines do not specify how the DTOT's should recommend frequency or duration of lessons.

Queensland's *Controlled Environment Driver Training Guidelines* (Department of Transport and Main Roads, 2021) emphasises responding to individual learner circumstances and does not make recommendations around frequency or duration of lessons:

> … consideration should be given to offering flexibility of approach and adapting learning principles to the needs of individuals, including those students with physical or mental health challenges. Driver trainers are not expected to conduct clinical assessments of special needs or challenges, but as educators there is a responsibility to be sensitive to these issues and to try to respond to them. Unfortunately, there is little research and evidence to prescribe specific driver training techniques for students with special needs; however, the key principle is to try to understand their circumstances and be as flexible in the conduct of training and communication methods as is reasonably practicable (2021, p.11).

The UK's *National standard for driver and rider training* (National standard, 2020) outlines what a driver instructor should know when training learner drivers. It describes a client-centred approach which responds to individual needs and takes into account to prior knowledge and experience of the learner. It does not provide guidance on frequency or duration of lessons.

4. Evidence for on-road driving lessons

There is a notable lack of evidence regarding the efficacy of on-road driving lessons for people with disabilities. A 2014 systematic review of occupational therapy assisted driver rehabilitation notes:

> while it is our experience that the most common intervention approach used in clinical practice is a series of lessons with a driving instructor, we were unable to identify any studies that evaluated this intervention approach. This kind of intervention has received very limited description in the literature which may be due to the heterogeneous nature of the training provided. (Unsworth & Baker, 2014, p.112)

While there is some efficacy data published since 2014, the lack of evidence of on-road driving lessons for people with disabilities is noted in almost all studies referenced in this paper (AustRoads & National Transport Commission, 2022; Berndt et al, 2022; Vindin et al, 2021; Department of Transport and Main Roads, 2021; Dun et al, 2020; Sangrar et al, 2019; Wilson et al, 2018; Lindsay & Stoica, 2018; Unsworth et al, 2015; George et al, 2014). For example, as recently as 2021, Australian researchers in Perth and Sydney could claim to have completed the first experimental on-road driving training intervention study for people with ASD (Vindin et al, 2021, p.3708).

4.1 General

In a recent interview-based study of Australian DTOTs looking at self-reported clinical reasoning regarding recommendations for interventions, Berndt et al note that:

> Participants asserted that peer-reviewed scientific research evidence for particular driver rehabilitation interventions was sparse, so they often deferred to clinical judgment and experience to guide practice. In the absence of specific driver rehabilitation intervention research evidence, general evidence was transferred across to a driver rehabilitation context, applied and then evaluated (Berndt et al, 2022, p.442).

Unfortunately, the authors do not elaborate on what this general evidence consists of. Participants reported factors related to on-road driving lessons as crucial to their decision making. For example, participants noted that in order to determine whether a skill was acquired, they needed to observe the skill being implemented across multiple lessons, rather than just once during an assessment. Responses also imply that a DTOT will create a hypothesis about the learner's driving ability and then test the hypothesis over multiple lessons.

Breault et al (2019) found young learners with disabilities took longer on average to learn to drive compared to young people without disabilities but did not provide details about average duration or frequency of lessons.

In their review, Sangrar et al (2019) found interventions including in-vehicle training could reduce driver errors and improve control of vehicle for older drivers. However, as the

interventions generally included multiple components (e.g., simulator training and group education) it is unclear how much of the effect could be attributed to on-road lessons. Also, the on-road component of training in these studies was generally limited to one or 2 sessions. Similar findings for older drivers were reported by Castalucci et al (2020). Beanland and Huemer (2021) raise the same concern regarding one- or 2-day driver training programs for all post-license drivers.

4.2 Autism Spectrum Disorder

A 2019 systematic review reported on 3 papers recommending strategies to assist people with ASD to drive. Strategies included shorter lessons, repetitions of lessons and regular, frequent and consistent lessons (Lindsay, 2019). The necessity for repeating lessons could be a reason people with ASD often take longer to learn to drive (Tyler, 2013).

The use of frequent repetition of lessons was supported in two publications reporting on an interview-based study of driving instructors (Myers et al, 2019; Myers et al, 2021). These studies always noted other specific strategies around duration and frequency of on-road driving lessons. One driving instructor suggested a typical pattern was 24hrs formal instruction from a driving instructor/OT plus another 200 hours of driving practice with parents/carers. Others described requiring 3 to 4 times more hours of on-road practice for people with ASD compared to those without. The authors suggested lessons can continue for 2-3 years. Instructors often recommended a course of driving lessons, followed by months or years of on-road practice with informal supports. During this time students were instructed to work on foundational pre-driving skills (e.g., learning to ride a bike or catch public transport independently) after which they may return for another course of driving lessons.

Participants in the Myers et al study predicted that around 30% of their students eventually got their license (Myers et al, 2019; Myers et al, 2021). This is consistent with evidence that 1 in 3 young people with ASD acquire their driver's license (Curry et al, 2018).

In 2018-2019, an Australian team of researchers completed a scoping review and RCT to examine interventions for young learner drivers with autism (Wilson et al, 2018; Vindin et al, 2021). The scoping review supports the suggestion raised in other studies (Myers et al, 2021; Myers et al, 2019; Lindsay, 2019; Tyler, 2013) that young drivers with ASD may require more lessons of shorter duration compared to those without ASD. In a survey of 388 respondents, Shepard et al (2022) found drivers with ASD typically required 20-40 professional driving lessons compared to people without who required on average 0-20 lessons, and driver with ASD typically got their license later. This is consistent with the only other quantified recommendation of an average of 24 lessons (Myers et al, 2019).

Wilson et al's (2018) scoping review found interventions reporting simulator or computer-based training but found no studies examining on-road driving lesson interventions. To address this gap, the research team designed an RCT to assess the efficacy of an on-road driving program for 72 young people with ASD (Vindin et al, 2021). In this study, both the intervention and control group were given 10 driving lessons with driving instructors who were not DTOTs. The

intervention group lessons were delivered by instructors trained in an ASD specific driving program. The control group lessons were delivered by instructors with no additional training. The researchers found large effect sizes for both groups but found no statistically significant difference between groups. It is noteworthy that both groups showed significant benefit after a course of on-road driving lessons with mainstream professional driving instructors. However, the authors note there is a possibility of self-selection bias resulting in a group of driving instructors with interest or experience in training young people with ASD.

4.3 Traumatic brain injury

Duration of driver training after traumatic brain injury depends on the severity of the injury (Schultheis & Whipple, 2014). Estimates for return to driving after TBI range from 42% to 98%. In their sample of 48 people with traumatic brain injury, Stolwyck et al (2019) found 31 were fit to drive following an assessment from an occupational therapist, while 9 of the 17 who failed the assessment were recommended take one or more driving lessons before being reassessed. All those who underwent driving lessons were re-assessed and cleared to return to driving. However, the report does not make clear how many lessons were required for the cohort of participants who failed the initial test.

Ross et al (2018) found in an Australian sample of 340 people with traumatic brain injury, 72% passed the initial post-injury driver assessment and of the 28% who failed the initial assessment, 98% passed after an average of 7 driving lessons (14 specialist driving instructor hours) and 2.5 on-road assessments (9.8 OT hours and 3.8 specialist driving instructor hours). Only 7 out of the 340 were not able to return to driving.

5. References

AustRoads & National Transport Commission. (2022). *Assessing fitness to drive for commercial and private vehicle drivers*. Australian Government. https://austroads.com.au/publications/assessing-fitness-to-drive/ap-g56

Beanland, V and Huemmer, I. (2021) *The effectiveness of advanced driver training*. Waka Kotahi NZ Transport Agency research report 677. https://nzta.govt.nz/assets/resources/research/reports/677/677-the-effectiveness-of-advanced-driver-training.pdf

Berndt, A., Hutchinson, C., Tepper, D., & George, S. (2022). Professional reasoning of occupational therapy driver rehabilitation interventions. *Australian Occupational Therapy Journal*, *69*(4), 436–446. https://doi.org/10.1111/1440-1630.12804

Breault, C., Giroux, L., Gauvreau, A., Belanger, S., Lamontagne, M.-E., & Morales, E. (2019). Acceptability of the process of obtaining a driver's license by young people with and without disabilities. *Journal of Accessibility and Design for All*, *9*(1), 90–117. https://doi.org/10.17411/jacces.v9i1.198

Castellucci, H. I., Bravo, G., Arezes, P. M., & Lavallière, M. (2020). Are interventions effective at improving driving in older drivers?: A systematic review. *BMC Geriatrics*, *20*(1), 125. https://doi.org/10.1186/s12877-020-01512-z

Curry, A. E., Yerys, B. E., Huang, P., & Metzger, K. B. (2018). Longitudinal study of driver licensing rates among adolescents and young adults with autism spectrum disorder. *Autism: The International Journal of Research and Practice*, *22*(4), 479–488. https://doi.org/10.1177/1362361317699586

Department of Transport and Main Roads. (2021). Controlled environment driver training guidelines. Queensland Government. https://www.tmr.qld.gov.au/-/media/busind/accreditations/driverandridertrainers/Controlled-Environment-Driver-Training-Guidelines.pdf?la=en

Di Stefano, M & Ross, P. (2018). *VicRoads Guidelines for Occupational Therapy Driver Assessors* (3rd edition). Roads Corporation Victoria, Melbourne.

George, S., Crotty, M., Gelinas, I., & Devos, H. (2014). Rehabilitation for improving automobile driving after stroke. *Cochrane Database of Systematic Reviews*, *2*, CD008357. https://doi.org/10.1002/14651858.CD008357.pub2

Myers, R. K., Bonsu, J. M., Carey, M. E., Yerys, B. E., Mollen, C. J., & Curry, A. E. (2019). Teaching autistic adolescents and young adults to drive: Perspectives of specialized driving instructors. *Autism in Adulthood Knowledge Practice and Policy*, *1*(3), 202–209. https://doi.org/10.1089/aut.2018.0054

Myers, R. K., Carey, M. E., Bonsu, J. M., Yerys, B. E., Mollen, C. J., & Curry, A. E. (2021). Behind the wheel: Specialized driving instructors' experiences and strategies for teaching autistic adolescents to drive. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*, *75*(3), 7503180110p1. https://doi.org/10.5014/ajot.2021.043406

National standard for driver and rider training. (2020). Driver and Vehicle Standards Agency. https://www.gov.uk/government/publications/national-standard-for-driver-and-rider-training/national-standard-for-driver-and-rider-training#unit-2---design-learning-programmes

Lindsay, S. (2017). Systematic review of factors affecting driving and motor vehicle transportation among people with autism spectrum disorder. *Disability and Rehabilitation*, *39*(9), 837–846. https://doi.org/10.3109/09638288.2016.1161849

Lindsay, S., & Stoica, A. (2017). A systematic review of factors affecting driving and public transportation among youth and young adults with acquired brain injury. *Brain Injury*, *31*(10), 1257–1269. https://doi.org/10.1080/02699052.2017.1321140

Ross, P. E., Di Stefano, M., Charlton, J., Spitz, G., & Ponsford, J. L. (2018). Interventions for resuming driving after traumatic brain injury. *Disability and Rehabilitation*, *40*(7), 757–764. https://doi.org/10.1080/09638288.2016.1274341

Sangrar, R., Mun, J., Cammarata, M., Griffith, L. E., Letts, L., & Vrkljan, B. (2019). Older driver training programs: A systematic review of evidence aimed at improving behind-the-wheel performance. *Journal of Safety Research*, *71*, 295–313. https://doi.org/10.1016/j.jsr.2019.09.022

Sheppard, E., van Loon, E. & Ropar, D. (2022). Dimensions of Self-Reported Driving Difficulty in Autistic and Non-Autistic Adults and their Relationship with Autistic Traits. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05420-y

Schultheis, M. T., & Whipple, E. (2014). Driving after traumatic brain injury: evaluation and rehabilitation interventions. *Current Physical Medicine and Rehabilitation Reports*, *2*(3), 176–183. https://doi.org/10.1007/s40141-014-0055-0

Stolwyk, R. J., Charlton, J. L., Ross, P. E., Bédard, M., Marshall, S., Gagnon, S., Gooden, J. R., & Ponsford, J. L. (2019). Characterizing on-road driving performance in individuals with traumatic brain injury who pass or fail an on-road driving assessment. *Disability and Rehabilitation*, *41*(11), 1313–1320. https://doi.org/10.1080/09638288.2018.1424955

Tyler S. (2013). Asperger's syndrome: the implications for driver training methods and road safety. *Journal of the Australasian College of Road Safety*, *24*, 55–62.

Unsworth, C. A., & Baker, A. (2014). Driver rehabilitation: a systematic review of the types and effectiveness of interventions used by occupational therapists to improve on-road fitness-to-drive. *Accident; Analysis and Prevention*, *71*, 106–114. https://doi.org/10.1016/j.aap.2014.04.017

Unsworth, C., Harries, P., & Davies, M. (2015). Using Social Judgment Theory method to examine how experienced occupational therapy driver assessors use information to make fitness-to-drive recommendations. *The British Journal of Occupational Therapy*, *78*(2), 109–120. https://doi.org/10.1177/0308022614562396

Vindin, P., Cordier, R., Wilson, N. J., & Lee, H. (2021). A driver training program intervention for student drivers with autism spectrum disorder: A multi-site randomised controlled trial. *Journal of Autism and Developmental Disorders*, *51*(10), 3707–3721. https://doi.org/10.1007/s10803-020-04825-5

Wilson, N. J., Lee, H. C., Vaz, S., Vindin, P., & Cordier, R. (2018). Scoping review of the driving behaviour of and driver training programs for people on the autism spectrum. *Behavioural Neurology*, *2018*, 6842306. https://doi.org/10.1155/2018/6842306

Augmentative and Alternative Communication Devices and Motor Neurone Disease

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The TAPIB Research and Capability team take care to ensure the research presented is accurate at the time of writing. Due to the nature of our work, we are not able to ensure that all relevant research has been considered in the development of this document or that information remains accurate after publishing.

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2. Summary

Multidisciplinary care is important in the assessment and management of motor neurone disease (MND). 80% of individuals with MND experience communication difficulties at some point during the development of the disease. Augmentative and Alternative Communication (AAC) devices are associated with higher quality of life for people with MND and their carers.

AAC devices can be used for different forms of digital communication including text-to-speech, access to web browsing, emails, social media etc. All AAC device assessments should cover the individual's present communication status, cognitive and language abilities and challenges, literacy abilities/limitations and ability to use and understand symbols, as well as physical abilities and challenges, seating and positioning, visual-spatial and perceptual abilities and challenges, and how to implement the system of AAC device usage. Therefore, a multidisciplinary approach may be required.

We did not find any evidence that an occupation therapist can independently assess individuals with MND for assistive technology (AT) for communication or specifically for AAC devices. Sources suggest that the speech and communication of an individual with MND should be assessed by a speech pathologist, and that a speech pathologist can assess the most appropriate AAC device and provide training in their use. The role of the occupational therapist includes ensuring AAC devices are integrated with other ATs and setting up and physically accessing AAC devices (see Section 4.1.3). The literature confirms that assessment and scripting of AACs in individuals with MND benefits from a multidisciplinary approach.

3. Motor Neurone Disease

MND is a group of diseases that affect nerve cells called motor neurons. In MND, the nerves become damaged and start to die, causing muscles to start to weaken and waste away (MND Australia, 2024c). Areas that may be affected by MND include nutrition, respiration and communication (MND Australia, 2024b; National Institute for Health and Care Excellence (NICE), 2019).

3.1 Communication

More than 80% of people with MND will experience communication difficulties at some point in the disease trajectory (MND Australia, 2021a). The speech of individuals with MND can deteriorate over the period of a few months and this one of the most problematic symptoms of MND according to people living with MND (Royal College of Speech & Language Therapists, n.d.). There is evidence that early ACC device intervention is associated with a higher quality of life for both patients and carers (Royal College of Speech & Language Therapists, n.d.).

3.2 Multidisciplinary Teams

The overwhelming consensus in the literature is that the management of communication difficulties experienced by individuals with MND requires a coordinated, multidisciplinary approach (Motor Neurone Disease Association (MNDA), 2025; MND Australia, 2021a; NICE, 2019, p. 11).

MND Australia states:

A coordinated care approach can help people with MND live better for longer. Known as multidisciplinary care, this involves engaging with a team of health professionals from a range of disciplines (MND Australia, 2024c).

According to the NICE guidelines for the assessment and management of MND, the multidisciplinary team should include the following professionals:

- neurologist
- specialist nurse
- dietitian
- physiotherapist
- occupational therapist
- respiratory physiologist or a healthcare professional who can assess respiratory function
- speech and language therapist
- a healthcare professional with expertise in palliative care (MND palliative care expertise may be provided by the neurologist or nurse in the multidisciplinary team, or by a specialist palliative care professional) (NICE, 2019, pp. 12-13).

4. Augmentative and Alternative Communication Devices

AAC devices are an important clinical intervention for many people with complex communication needs, including people with MND (American Speech-Language-Hearing Association (ASHA), 2025; MNDA, 2025). AAC devices refer to all the ways in which people communicate without talking (ASHA, 2025). They comprise systems and strategies used to augment or replace natural speech for people with complex communication needs (Conlon & Zupan, 2024, p. 3). AAC devices can be no-tech or low-tech such as:

- gestures and facial expressions
- writing and drawing
- spelling words by pointing to letters
- pointing to photos, pictures or written words (ASHA, 2025; MND Australia, 2021a).

AAC devices can also be high-tech such as:

- applications on an iPad or tablet to communicate
- specialised software
- speech-generating devices
- eye gaze or electromyography (EMG) technology
- voice and message banking
- brain/computer interface (ASHA, 2025; MND Australia, 2021a).

Accessing systems for AAC devices can include a head pointer mouse, a track ball, a switch, eye-gaze or software systems. AAC devices can be used as part of an integrated AT system (Speech Pathology Australia, 2018, p. 5). This means a device used for communication can also be used to drive an electronic wheelchair, operate environmental control systems or to access IT such as mobile phones and computers (ASHAWIRE, 2021; Speech Pathology Australia, 2018, p. 5). These IT devices can be used for access to electronic communication like web browsing, social media and emails (ASHAWIRE, 2021; Cambridge University Hospitals, 2023; Hemsley et al., 2017; MNDA, 2025; Speech Pathology Australia, 2018, p. 5).

Almost all domestic, social and learning activities involve some form of communication with other people, so it is important that individuals have access to language in everyday situations which includes having access to an AAC device (Speech Pathology Australia, 2024).

4.1 AAC Device Assessments

In a 2014 presentation by the Augmentative Communication Program from the Boston Children's Hospital, which took place at an International Society for Augmentative and Alternative Communication (ISAAC) conference, team AAC assessments for children with complex communication needs were discussed. The presenters included speech language pathologists and occupational therapists as members of the AAC assessment and stated that, in any setting, an AAC assessment should cover the following:

- present communication status
- physical abilities and challenges
- seating and positioning
- visual-spatial- perceptual abilities and challenges
- cognitive and language abilities and challenges
- literacy abilities and limitations
- the ability to use and understand symbols
- environmental concerns
- how to implement the system (Russel & Buxton, 2014, p.7).

The presenters also discussed the four basic questions at the core of AAC assessments:

- What are the child's communication needs or goals?
- What are the child's strengths and abilities?
- What barriers are preventing the child from achieving his or her full communication/participation potential?
- What aids and adaptations (e.g. AAC devices or systems, environmental modifications) will best accomplish the child's goals given his or her strengths and abilities, and current circumstances? (Russel & Buxton, 2014, p. 8).

The MND Association in the United Kingdom states that AAC service delivery can be complex and that the successful use of a system often relies on good teamwork at the assessment stage and that collaboration between speech and language therapy, occupational therapy and physiotherapy should be considered where necessary (MNDA, 2025).

4.1.1 Speech Pathologists

For individuals with MND, timely referral to a speech pathologist is important. The speech and communication of an individual with MND should be assessed by a speech pathologist soon after diagnosis and reviewed at each clinic visit (MND Australia, 2021a; NICE, 2019, p. 24).

Speech pathologists can advise on strategies for communication, assess and script the most appropriate communication aids/AAC devices based on individual needs, train individuals in their use, and assist with access to voice and message banking (MNDA, 2022; MND Australia, 2021a; Speech Pathology Australia, 2018, p. 6).

As part of the Michigan Occupational Therapy Association (MiOTA), Smith et al. presented on the role of the occupational therapist and speech language pathologist in working with AACs. They state that the speech language pathologist's role, among other things, is to evaluate and assess the need for AAC (n.d., p. 12).

4.1.2 Occupational Therapists

In the MND Association's occupational therapy for motor neurone disease guide, endorsed by the Royal College of Occupational Therapists, it is stated that an occupational therapist can help individuals with MND to participate in functional activities that are important to them. The occupational therapist can assess and advise on, among other things:

- optimisation of meaningful activities of daily living, work, social participation and leisure opportunities for as long as possible, focusing on what is important to the person
- modification of the home environment to maximise function and mobility
- facilitating safe participation in functional activities as function declines
- posture and positioning
- fatigue management and conservation of energy
- psychological, cognitive and behavioural strategies
- facilitating timely provision of adaptive equipment for current and anticipated needs
- providing support around physical, emotional and spiritual issues, including open discussions about planning ahead, death and dying
- help the person adjust to changing roles
- supporting the person and their family members to express choice and control, and support them to develop their life goals together

- support for family and carers, throughout the course of the condition, and in bereavement (MNDA, 2022, p. 9).

In terms of communication, occupational therapists should work closely with the speech and language therapist to assess the person's communication needs. An occupational therapist may support a person's ability to communicate with:

- seating, positioning, wrist, hand, finger, head and neck supports
- switches and pointers
- mobile arm supports
- tables to support access to communication aids
- equipment to support computer use for communications such as email and social media
- environmental controls (MNDA, 2022, p. 30).

The occupational therapist may also give advice about home modifications, help to choose and adapt specialised equipment and help to assess and set up communication aids (MND Australia, 2024a).

The occupational therapist's role in AAC in particular is described in several sources. It can include assessing the physical access (direct selection or indirect selection) of a patient to things such as AAC and environmental control and ensuring AAC equipment is integrated with other ATs, such as environmental control systems and personal computers or tablets (NICE, 2019, p. 25; Russel & Buxton, 2014, pp. 11-12). The amount of involvement depends on an individual's physical and sensory capacity. For example, some individuals pay need an AAC fitted to their wheelchair (Speech Pathology Australia, 2018, p. 6).

The Capability Framework for Occupational Therapists Working with Assistive Technology includes capabilities for Communication Assistive Technology. It states that the foundational practitioner supports the speech pathologist to select the most suitable AAC device for the person in question. The intermediate practitioner works with the speech pathologist to select the best AAC device while the senior practitioner description contains no reference to speech pathologists (Occupational Therapy Australia, 2025, pp. 43-44). However, according to the framework, senior practitioners "critically evaluate and refine AAC solutions, integrating multidisciplinary input to optimise outcomes" which may suggest the involvement of a speech pathologist (Occupational Therapy Australia, 2025, p. 43).

In terms of collaboration, the occupational therapist's role is to work with the speech therapist to understand what system the client uses, how they access it and where they are in learning their system/language development (Smith et al., n.d., p. 12). More specifically, specialists such as occupational therapists can work with speech pathologists on things such as:

- seating, positioning, wrist supports, switches, pointers, mobile arm supports and tables
- access to communication aids

- access and use of a computer, tablet, phone, apps, voice banking and environmental controls (MND Australia, 2021a).

4.1.3 Assistive Technology

MND Australia advise that a General Practitioner (GP) or multidisciplinary team can arrange a referral to a speech pathologist or occupational therapist who can provide advice on how to modify communication as symptoms progress, information on voice banking and recommend AT for alternative ways of communicating (MND Australia, 2020, p. 15). They also state that an occupational therapist, speech pathologist or physiotherapist can advise about AT items for communication, as well as comfort, mobility, function, independence and carer safety (MND Australia, 2020, p. 16).

MND Australia also states that assessment for AT for daily living can be undertaken by an occupational therapist, physiotherapist, speech pathologist or nurse, depending on the area of expertise and the availability of professionals in any particular locality, to ensure the AT is provided to meet the identified need for that individual (MND Australia, 2021b). No such statement is made with regards to the assessment for AT for communication.

5. References

American Speech-Language-Hearing Association (ASHA). (2025). *Augmentative and Alternative Communication (AAC)*. https://www.asha.org/public/speech/disorders/aac/?srsltid=AfmBOopNJTk5a-R68mOPysrIviKDFSat6125i4Dj-Z-OffPqo8F-WOX

ASHAWIRE. (2021, November 16). *What Are Key Considerations When Selecting High-Tech AAC?* https://leader.pubs.asha.org/do/10.1044/2021-high-tech-aac/full/#:~:text=In%20some%20cases%2C%20AAC%20devices%20can%20also,be%20as%20simple%20and%20straightforward%20as%20possible

Cambridge University Hospitals NHS Foundation Trust (2023, September 13). *Online safety for clients accessing augmentative and alternative communication (AAC)*. https://www.cuh.nhs.uk/patient-information/online-safety-for-clients-accessing-augmentative-and-alternative-communication-aac/#:~:text=Many%20of%20these%20devices%20also,social%20media%20and%20online%20networking

Conlon, C., & Zupan, B. (2024). The knowledge, confidence and attitudes of Australian speech-language pathologists in augmentative and alternative communication for children and young people. *Journal of Clinical Practice in Speech-Language Pathology*, *26*(1), 3–19. https://doi.org/10.1080/22000259.2024.2316925

Hemsley, B., Balandin, S., Palmer, S., & Dann, S. (2017). A call for innovative social media research in the field of augmentative and alternative communication. *Augmentative and*

Alternative Communication, *33*(1), 14–22. https://doi.org/10.1080/07434618.2016.1273386

Motor Neurone Disease Association (MNDA). (2025). *AAC for MND*. https://www.mndassociation.org/professionals/management-of-mnd/aac-for-mnd

Motor Neurone Disease Association (MNDA). (2022). *Occupational therapy for motor neurone disease*. https://www.mndassociation.org/sites/default/files/2022-11/Occupational%20therapy%20for%20MND.pdf

MND Australia. (2024a, June). *Equipment & home modifications.* https://www.mndaustralia.org.au/mnd-connect/living-with-mnd/equipment-assistive-technology-home-modifications

MND Australia. (2024b, June). *Speech & communication*. https://www.mndaustralia.org.au/mnd-connect/living-with-mnd/speech-communication

MND Australia. (2024c, March). *What is motor neurone disease?* https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd

MND Australia. (2021a, June). *Dysarthria & communication*. https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/managing-symptoms/communication-in-mnd

MND Australia. (2021b, June). *Role of assistive technology in MND*. https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/assistive-technology

MND Australia. (2020). *Motor Neurone Disease More Facts*. https://www.mndaustralia.org.au/getmedia/7ddb1ee3-36d1-4f42-b2fa-60c44eb57097/More-Facts-about-MND.pdf

National Institute for Health and Care Excellent (NICE). (2019, July 23). *Motor neurone disease: assessment and management*. https://www.nice.org.uk/guidance/NG42/chapter/Recommendations#recognition-and-referral

Occupational Therapy Australia. (2025, March 31). *Capability Framework for Occupational Therapists Working with Assistive Technology*. https://ota-directus-prod-fedmhjdvaceqf3g7.australiasoutheast-01.azurewebsites.net/assets/69464b7e-48c5-4182-977c-7de540872f19.pdf

Royal College of Speech & Language Therapists. (n.d.). *Supporting people living with motor neurone disease*. https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/rcslt-motor-neurone-factsheet.pdf

Russell, S. S. & Buxton, J. C. (2014). *Access is the KEY to AAC: The Role of OT* [PowerPoint Slides]. International Society for Augmentative and Alternative Communication. Lisbon,

Portugal. https://www.childrenshospital.org/sites/default/files/media_migration/f50061b5-a363-4b76-9b8e-5fec942f693d.pdf

Smith, D., Underhill, K., & Ward, M. (n.d.). *OT, SLP & AAC* [PowerPoint Slides]. Michigan Occupational Therapy Association. https://miota.org/docs/MiOTA_AAC_Presentation_Final_Copy.pdf

Speech Pathology Australia. (2018, September 14). *Speech Pathology Australia's Submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry: Assistive Technology*. https://www.speechpathologyaustralia.org.au/Common/Uploaded%20files/Smart%20Suite/Smart%20Library/7526676d-3f8d-47ce-8603-0968d54eb5ac/SPA%20Submission%20NDIS%20AT%20FINAL%2014092018.pdf

Speech Pathology Australia (2024, August 29). *Augmentative and Alternative Communication*. https://www.speechpathologyaustralia.org.au/Public/Public/Comm-swallow/Aug-alt-strategies/Augmentative-Alternative-Communication.aspx