



Institute for Medical Research

2024 Economic Impact Study – Cost Diary Help Booklet

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Ethics

- University of Tasmania Human Research Ethics Committee (approval H0014183).
- The AMSLS Information Sheet can be downloaded from www.msaustralia.org.au/AMSLS

Need help?

For support, any questions or concerns please contact the AMSLS team:

(03) 6226 4739

<u>AMSLS.info@utas.edu.au</u>
https://www.msaustralia.org.au/amsls/

When you are ready to return your *Cost Diary,* please use the Reply-Paid envelope provided or send to:

Menzies Institute for Medical Research
University of Tasmania
Australian MS Longitudinal Study
Reply Paid 77465
HOBART TAS 7000

Thank you!

We appreciate 6 months of recording costs is a big ask, and your selflessness means we have the real-life data necessary to show the financial impact MS can have and provides vital data for advocacy efforts to get those with MS the support they need the most.

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SECTION 1:

GENERAL INSTRUCTIONS

General overview of what to expect and how to record your costs

Over the next 6 months, we would like you to record all items and services you purchase or receive that <u>may</u> be linked with your MS. This includes everything from MS symptom management and measures to prevent disease progression, through to maintaining your overall wellbeing to limit the impact of MS.

As we are calculating the cost to you individually as well as Australia as a whole, we ask you to record all items and service usage, regardless of whether you personally paid for them or they were given to you, funded, or otherwise financed.

1.1 What to keep in mind when recording your costs

While more specific category descriptions and examples are laid out in the following sections, a few general guidelines apply to all costs:

- Absolute accuracy is NOT necessary: The exact cent, kilometre, or purchase date
 don't matter; but not recording anything will mean that cost doesn't exist. If you
 can't find the receipt and can't quite remember the full details, estimating is more
 than acceptable.
- If you're unsure about a cost, record it anyway: We know it's often hard to separate MS from other causes, such as aging, or the potential impact of other conditions and life in general. Similarly, your activities may be aimed at improving your overall wellbeing and not specifically targeted towards MS. If in doubt, record the cost and add a note of explanation. It's easy for us to exclude a cost if necessary, but we can't include a cost we don't know about.
- Please record <u>all</u> medications and supplements: As all medications and supplements
 can impact your overall wellbeing, please record everything you use, regardless of
 the reason you're using it.
- Record barcodes whenever possible for purchases: Barcodes are unique even for different sizes of the same product. As such, providing the barcode is by far the most accurate way to identify your exact purchase, and means you will need to provide minimal other details.
- Each trip only needs to be recorded in one spot, regardless of how many MS related costs occurred on that trip: When you look at the *Cost Diary*, you will see there are multiple places to record MS related travel costs. This, however, is purely for convenience, and where you have a trip with multiple MS-related costs (e.g. a doctor's appointment, blood test and a pharmacy purchase in the same trip), the associated travel only needs to be recorded once.
- Mistakes are fine: There is nothing wrong with crossing out mistakes in the Diary, and if you accidentally put something in the wrong category it's OK to leave it there (as long as you provide the details we need of course!) We are also more than happy to send you additional pages of any category if required.

1.2 Choosing a routine for your *Cost Diary* completion

There is no 'right' routine for entering costs. Every one of our AMSLS family will have a different lifestyle and will differ in the type and number of costs they'll need to record. You are the person in the best position to know what will work for you.

The below are just suggestions of different ways that may work for you if you would like some ideas. The most important distinction will be whether you will feel more comfortable recording every cost as soon as you get home (option 1), or whether you'd be more likely to have a system to safely store relevant details so you can sit down and transfer multiple costs in batches when you have more time (option 2).

You may even realise you need to do things differently throughout the Diary period, depending on what is going on. Only you will know, but we do suggest you take time to think about it and start with something that may feel 'over the top'. We know life can get in the way of the best intentions, and not taking the time up front to decide on a suitable plan is more likely to lead to the Diary being abandoned.

1.2.1 Option 1: Recording costs on the day they occur

This option is going to be most suitable for people who know they will have the time and motivation as soon as they get home (or sometime before they go to bed) to record any costs they have incurred that day.

While this method will be useful to ensure the details of costs are still fresh in your mind (and you still know where the receipt is), it is unlikely that you will incur costs every day, so the key will be to have a physical reminder to jog your memory on days you do have costs.

Options may include:

- Using the *Cost Diary* itself as a physical prompt to remind you to record costs: This would mean putting the Diary (and a pen) in a prominent location you would see every day, such as where you keep your keys, on the coffee table in the loungeroom, or even on the kitchen bench.
- Using another visual (or other sensory) prompt to remind you to record costs: This is the same concept as using the Diary itself, but lets you keep the Cost Diary 'away' in a cupboard or on your desk. The key will be choosing an object that is 'out of place' so it doesn't easily get ignored. Examples may be putting a specific magnet in the middle of the fridge door that you'll see each time you open the fridge, or a hairband on your (outside) door handle that you'll see as soon as you get home, or even a spot of blutack on the tv remote you'll see or feel when you sit down in the evening.
- If it's practical, you could also consider putting something near your landline (or computer), or moving where your phone's calling app is located as an extra prompt to remind you to get the *Cost Diary* to complete appointment details while you're making bookings.

1.2.2 Option 2: Recording costs later when you have time (and/or in batches)

This option is going to be the most practical for people who know they'll be unlikely to have the time or energy to transfer costs into their Diary immediately, and are more likely to sit down when time permits to fill in the details of all costs from the last week, fortnight or month.

The key to this method is going to be ensuring you have a way to retain the details of your costs, and setting yourself time to transfer these costs before the details are lost or the number you need to transfer becomes too daunting.

Options for retaining the cost details may include:

- **Keeping a storage container** (folder, envelope, plastic sleave) **and pen and paper** near where you put your keys, so you can deposit relevant receipts, or jot down a few key details as a reminder as soon as you get home.
- Using a small physical notebook or electronic note app on your phone to jot down key details 'on the go' (waiting in a queue, in a waiting room, or as soon as you get back to the car).

Once you have a good method for retaining your cost details, **set yourself some regular calendar reminders** to book in time to transfer the costs. These reminders need to be:

- Somewhere that is part of your routine (e.g. as an entry in a physical or electronic calendar or diary you already use; as an entry in a reminder app that will notify you when the time comes; as dates on a piece of paper on the fridge that you can physically cross off),
- 2. Set at times where you are most likely to be able to action them (i.e. when you know you'll be home and have time to spend on the Diary, rather than an alert during work hours that you'll likely dismiss and forget), and
- 3. **Set at regular intervals** that aren't going to make it too daunting for you to transfer your costs. This may be weekly, fortnightly or monthly depending on your normal routine, how many costs you are likely to incur, and how long you feel confident you will be able to recall all necessarily details for costs that may not otherwise be available on receipts, or written down in your key detail notes.

After you get going, you may need to tweak how you retain cost details and the reminders you set yourself, but taking time up front to put in place a routine you *think* may work for you will give you a good starting point, and will mean your brain can happily forget about the *Cost Diary* in between your allocated 'recording' sessions.

1.3 What happens at the end of the 6-month Cost Diary period

Around five and a half months from when you received your *Cost Diary*, you will receive your reply-paid envelope and a short checklist in the post. When your *Cost Diary* finish date is reached (i.e. 6 months after your start date), you can run through the checklist at your leisure to finalise your *Diary* and double check you have provided as much information as you are able. At this point, your job is done, and you can then return your Diary and checklist in the Reply-Paid envelope, just as you would a regular survey.

If you are interested in the outcomes from this *Economic Impact* study, keep an eye on the MS Australia website and the yearly AMSLS newsletter for details on when the report will be ready and how to access it.

SECTION 2:

COST CATEGORY DESCRIPTIONS AND EXAMPLES

2.1 The overall *Cost Diary* structure

As we need different details to calculate different types of costs, the *Cost Diary* has been divided into 4 main categories. These top-level categories are colour coded to assist with easier recognition of where the different types of costs should be recorded.

Section A - Your regular costs (apricot)

This section is for your regular, recurring weekly, fortnightly, or monthly costs, as well as any National Disability Insurance Scheme (NDIS) or *My Aged Care* funding you may receive. The costs in this section are ones you could budget for, even if the exact day you use the associated services may vary. They include costs such as memberships, subscriptions, regular services or appointments, and any routine travel linked to your MS.

Section B - Housing and long-term assets (yellow)

This section is for costs related to the structure of your vehicle or house, as well as any other non-disposable equipment that can reasonably be expected to have a longer life span (3 years or more) that you have bought or hired for your MS during the 6-months of the *Cost Diary* or in the 5 years leading up to it.

Section C - Purchases and hiring (blue)

This section is for any physical items you buy or hire to assist with your MS during the 6-months of the *Cost Diary* period.

Section D - Service usage and transport (green)

This section is for all non-routine appointments, services, assistance and advice received, and irregular or once off transport not recorded elsewhere during the 6-months of the *Cost Diary* period.

Section E - Notes and comments (purple)

This section is for you to record any information, comments, questions or extra details you would like to provide.

While there is no wrong way to complete the Diary, we do recommend taking your time to familiarise yourself with the Diary and the details required for the different types of costs. There is an index of examples located at the front of this booklet, so you can also browse through completed examples of some costs that may be similar to your own.

When you feel ready to begin, we recommend that you set aside an hour or so to get started with *Section A - Your regular costs* and *Section B - Housing and long-term assets*. These two sections contain costs that have already occurred, and by completing them up front, you will find that your focus during the 6-months of the *Cost Diary* period itself can be on the more irregular and one-off costs located in Sections C and D.

It may also be useful to keep the *Quick Start Guide* in the back of your *Cost Diary*. The middle of the guide contains a summarised version of the categories and example costs and may be useful as a guick reference to decide where a cost should ideally be recorded.



2.2 TRANSPORT

Whether it's the extra 5 minutes in the car to pick up your medication, or the visit to your local MS clinic, travel associated with MS can be one of the harder MS related costs to remember as it is often secondary to completing another task. In addition, some people may realise <u>all</u> their transport is affected by their MS, as each trip may require careful planning to ensure you have the support you need, or that any associated walking distance is minimised.

Unless you have minimal impact from MS and happen to only have a few MS related costs, it may seem overwhelming to think of recording every trip you make. Rest assured, **we do not need you to record the minutest detail of every trip**, and an approximation of the types of transport you use and how often you use them is all we ask.

To help you to feel comfortable with recording your transport, the following sections detail how we will calculate your transport costs, and a few methods you may consider adopting depending on your personal circumstances.

2.2.1 Which trips you need to record

The first decision you need to make with respect to recording your transport is the extent MS impacts your ability to get around. This will fall into two broad categories:

MS generally limits the type of transport you can take: If your MS symptoms limit the
transport options you can independently use, either during the travel itself or the
walking distance required to get to or from that transport, then record <u>ALL</u> your
transport regardless of the reason for the trip.

This may seem overwhelming for those who do have to plan their transport and also travel frequently, but we are happy for you to use weekly, fortnightly or monthly estimates. You do <u>not</u> have to carefully log every trip. See *2.2.4.7 - Example: Recording frequent transport when MS limits your travel options* for examples.

Please note: If you are in this category of limited travel options due to your MS and you have travelled for non-MS related reasons, please <u>only</u> record the transport details for that trip. For example, you should only record the travel to get to a non-MS related doctor's appointment. However, a doctor's appointment to discuss a concern linked to MS, should have <u>both</u> the appointment details <u>and</u> the associated travel recorded.

2. MS does not limit the type of transport you can take: If you can travel independently and MS has little or no impact on what type of transport you can use, then you should only record the transport directly associated with other MS related services you use or purchases you make. In general, this will mean whenever you record a cost for MS in the diary, you should also just be asking "did I have travel for this cost?" and if so, record the transport at the same time.

The following table indicates which means of travel you should be recording:

<u>DO</u> include transport provided by:	DO NOT include transport provided by:
 private vehicles (owned by you, family, neighbours or friends) taxis or Ubers public transport (bus, train, tram) community and ambulance transport planes or helicopters Any other cost incurring transport (including charging costs for outdoor mobility scooters or inter-city electric scooters) 	 walking and wheelchair travel bike riding non-electric scooters, roller- or inline skates, skateboards any other free, non-registered vehicle travel

2.2.2 Where to record your transport and how the cost is calculated

For your MS related transport costs, we will be using your entries to calculate the cost you have incurred **by transport type** over the 6 months:

- For non-privately owned transport (taxis, Uber, public transport), this will be the total in fares you have paid for that type of transport.
- For private vehicle transport (your own, or that of a friend or family member), this
 will be a combination of any parking you have had to pay, as well as the
 approximate running costs of that vehicle. These running costs incorporate petrol
 costs that are based on the total kilometres you have recorded, but it will also
 include a component to cover other private vehicle costs, such as registration,
 insurance, repairs and servicing.
- For transport where you have reduced or no personal cost, such as some ambulance services or community transport, we still calculate the cost to the provider of that transport (e.g. the government, your insurance, or other funding body), so please still record trips where you don't personally pay anything on the day.

To help remind you to record your transport costs, you will see most service usage sections throughout the *Cost Diary* contain the option to record your transport associated with that service usage. This includes:

- Section A Memberships, subscriptions and multi-day travel passes
- Section A Regular services and appointments
- D1 Appointments and other services
- D2 Medical tests and scans
- D4 Temporary hospital and health care admissions

In addition, there are two independent 'transport only' sections:

- Section A Regular transport (e.g. for work, regular shopping trips, or additional legs of transport that didn't fit in the associated service cost entry from Section A), and
- D3 Additional transport for any (non-routine) trips related to item purchases, and any other transport or additional legs of journeys that have not been recorded elsewhere.

Often you may also find that you have had multiple MS related costs that have been covered in a single outing, for example dropping into the pharmacy to buy your medication after your neurologist appointment. As we do not need to take into account the exact reason for each trip, **you only need to record each trip ONCE** in the Diary, and it doesn't matter which transport section you choose to record it in.



2.2.3 Transport – detailed information about what you need to enter

All transport related sections require the same details from you, and include:

- the type of transport you used (transport type),
- how long each leg of a trip took (travel time), and
- how much the trip cost you on the day (transport cost).

In addition to the above, we also need:

- the approximate distance covered for private vehicle travel only (distance), and
- how often you take the same trip for regular transport recorded in Section A (transport frequency).

2.2.3.1 Transport tables: Transport type

The "Transport type" column is to record the **mode** of cost incurring transport you used. This includes, but is not limited to the following:

- private vehicles (cars, motorbikes, vans, SUVs, utes, mobility scooters)
- taxis or Ubers
- public transport (bus, train, tram)
- community and ambulance transport
- air travel (planes, helicopters)

2.2.3.2 Transport tables: Travel time

The "travel time" column is to record the approximate **amount of time** you spent travelling **for an individual leg** of your trip; from the time you started moving in that type of transport, to the time you stopped at your destination.

The travel time can be rounded to the nearest 5 minutes for trips less than an hour, or 15 minutes for longer trips.

If you want to use the "My transport to and from this service is the same" flag to indicate the trip to your destination is the same as your trip home, it does <u>not</u> matter if the travel time for each leg is slightly different (e.g. it takes 21 minutes one way, and 26 minutes the other). You are welcome to just use a rough 'average' for your travel time (e.g. 25 minutes in the example given).

<u>DO</u> include in your travel time:	DO NOT include in your travel time:		
 Time spent in that mode of transport from when it starts moving, to when it stops at your destination. Stationary time that occurs between your start and destination points, such as red traffic lights, traffic delays, or public transport stops. 	 Any walking, cycling or other cost-free travel time taken to reach pick-up or dropoff points Any waiting time at travel origin or destination points, including any time spent waiting for public transport to arrive, or time spent in waiting rooms prior to appointments 		

2.2.3.3 <u>Transport tables:</u> **Distance (private car only)**

The "Distance" column is to record the approximate distance in kilometres of an individual leg of your journey. This is only required for private car travel, as it is used to calculate the equivalent cost of the trip that roughly covers the running costs of a private car, such as petrol, registration, insurance and repairs. These costs are incorporated in the fare you pay for taxis, Ubers and public transport, so we do not need to know the associated distance for travel in these other modes of transport.

While you are welcome to use Google Maps or your odometer to record precise distances if you wish, approximate distances to the closest 5km or so is fine.

If you want to use the "My transport to and from this service is the same" flag to indicate the trip to your destination is the same as your trip home, it does <u>not</u> matter if you take a slightly different route each way, or you have incorporated a non-MS related side trip.

<u>DO</u> include in your travel distance:	<u>DO NOT</u> include in your travel distance:	
Private vehicle travel only	 Any non-private vehicle transport, including walking, taxis, Ubers, trains, trams, buses, ambulances, community transport 	

2.2.3.4 <u>Transport tables:</u> The "My transport to and from this service is the same" checkbox

This checkbox is provided so you do not have to enter separate details for trips where you use the **same mode of transport and route** to get to and from your destination.

When using this checkbox, record the details for **one way** in the travel time (and distance) column(s), as we will double these values to calculate the total trip time and distance.

We know the exact time taken will not be identical in both directions, and that you may choose a slightly different route at different times of the day, but these slight discrepancies are quite OK, and should not stop you from using the checkbox if you choose.

If you do end up with a large delay in one direction (such as peak hour traffic, or an accident), you are still welcome to use the "My transport to and from this service is the same" checkbox, and just record the time taken as an average of the times taken to and from your destination.

DO use the "My transport to and from this service is the same" checkbox for:	DO NOT use the "My transport to and from this service is the same" checkbox for:
 Trips where you use one mode of transport for two legs of a trip where the route and time taken in both directions is roughly similar Private vehicle trips where the person who picked you up was different than the one who dropped you off The same transport legs as described above, even if other transport occurs in between those legs (e.g. 'Park and ride') 	 Different modes of transport to and from your destination, even if the time taken and route are identical (e.g. a ride with a friend one way, and a taxi trip home) The same mode of transport each way, but you take a considerably different route to get home



2.2.3.5 Transport tables: Transport cost

The "Transport cost" column is for the amount you have had to pay for that trip, either in fares or parking costs.

For private vehicles, running costs, such as petrol, are catered for by the *distance* you have recorded, so you only need to incorporate any fees you have paid for parking or tolls. These can be recorded to the nearest dollar on the 'total' line.

For trips where you have paid one fare to get to your destination and then another one to get back home, you are welcome to either record the full amount you have paid for the day (to the nearest dollar) on the 'total' line, or individually record the respective costs of each leg on the 'out' and 'back' lines.

If you have a **longer-term parking space** (a specific spot paid weekly or monthly), record the cost of the parking space in *Section A – memberships, subscriptions and multi-day travel cards*, and tick the "part of a travel pass" with no other associated cost in the "transport cost" column for the trips where you use that parking space.

Similarly, if you have a **public transport travel card** where you pay for unlimited travel (within zones) over multiple days or weeks, record the cost of the travel card in *Section A – memberships, subscriptions and multi-day travel cards*, and tick the "part of a travel pass" with no other associated cost in the "transport cost" column for the trips where you use that card.

Please remember to include all MS related travel, even if you receive funding or you are eligible for free community transport, as we still calculate the associated cost of these services to funding bodies and the government.

DO include in your travel cost:	DO NOT include in your travel cost:
 Parking and tolls for private vehicle travel All fares and taxes for non-private vehicle travel All travel for your MS, even if you personally don't pay for that transport 	Running costs of privately owned vehicles, such as petrol, registration, or insurance (* Please ensure you complete the distance travelled to cover these costs)

2.2.4 Transport – examples and scenarios

The following examples are just some of the ways you may choose to record various scenarios, but wherever you choose to record transport is fine, as long as *each trip is recorded only once*.

2.2.4.1 Example: A straight forward MS related trip using the same transport out and back

You've made an **appointment at your local MS society** on one of your days off to get some advice about your job. On the day, you decide to catch the **train** and you walk the 5 minutes to the train station, where your **return ticket costs you \$5.90**. The train arrives 15 minutes later and takes **12 minutes** to get to the stop you need.

The walk to the MS society office is quick, and you're a bit early, so end up sitting in the waiting room for 20 minutes. The appointment itself doesn't take as long as the hour that was booked either, and you find yourself with a spare 45 minutes before the next train will arrive to take you home. You decide to fill the time by grabbing the bread and milk you need at a local grocery store.

On the way home, the **train** trip takes **17 minutes**, which is a little longer than the trip out as there are a few extra stops that were by-passed on the first journey.

MS related costs to record:

- 1. The **appointment** at the MS Society:
 - Despite not using the total time allocated, the full one-hour appointment should be recorded in **D1 Appointments and services**.
- 2. The **travel** required to get to the appointment:
 - The transport is recorded along with the MS Society appointment details in D1 –
 Appointments and services by ticking the "Yes" checkbox for the Did you travel for this service?
 - As the same train line was used out and back, you may use the "My transport to and from this service was the same" checkbox, despite the slight differences in travel time each way. Use a rough average of the 'out' and 'back' times for the one-way travel time (12 minutes out, 17 minutes return, which is approximately 15 minutes each way).
 - *Transport cost*: The \$5.90 return fare can be rounded up to \$6.
 - Note that *Distance* is not required for train travel, so it is left blank.

D1 – Appointments and services

Did you travel for this service?	Transport type	Travel time	Distance	Transport cost	
Yes 🗸	To service: Train	0 0 : 1 5 h h m m	km	\$ 6 total	
Yes, but it's recorded elsewhere	My transport to ar	nd from this service <u>OR</u>	is the same	\$ out, and	1
No	Return by:	h h m m	km	OR Part of a travel pass*	



Other valid options for this scenario:

- 1. The transport details could easily be recorded elsewhere in the Diary (e.g. with another MS related service if you had attended more than one MS related service on the day, or as a stand-alone travel entry in D3 Additional Transport). If your trip has been recorded elsewhere, just tick the "Yes, but it's recorded elsewhere" checkbox in the Did you travel for this service? column for the MS Society appointment, and leave the rest of the transport details blank.
- 2. We chose to average the travel time to make use of the "My transport to and from this service is the same" checkbox, but it would have been equally valid to enter the "To service" and "Return by" details separately. I.e.:
 - a. Transport type (To service): "Train"
 - b. Travel time (To service): "00:12"
 - c. Transport type (Return by): "Train"
 - d. Travel time (Return by): "00:17"

Details not to record from this scenario:

- 1. The "no cost" travel to get to the appointment i.e. the walking to and from the train, or around the appointment and shopping trip.
- 2. Any of the "waiting" time, including waiting for the trains to arrive, and waiting to go in to the appointment.
- 3. The non-MS related purchases i.e. the groceries.

2.2.4.2 Example: A straight forward MS related trip using different transport types out and back

You have a **45-minute massage** booked to help relieve MS related muscle stiffness. Your friend happens to be visiting beforehand and gives you a **lift to the appointment**, and it takes **around 20 minutes** (to be honest, you were too busy chatting to really pay close attention). Google Maps tells you the route you took was **12km**.

After the massage, you grab a coffee and wait the 25 minutes for your usual **train home**. You don't need to buy a ticket as you just use your 28-day **public transport pass** you buy each month that gives you unlimited Zone 1 and 2 travel (it costs **\$180 every 4 weeks**). The massage worked; You're so relaxed you almost fall asleep on the **40-minute** ride home.

MS related costs to record:

- 1. The **massage** for your MS related muscle stiffness:
 - The 45-minute appointment should be recorded in **D1 Appointments and services**.
- 2. The **travel** required to get to and from the massage:
 - The transport is recorded along with the massage details in D1 Appointments and services by ticking the "Yes" checkbox for the Did you travel for this service?
 - **Travel to** the appointment:
 - o *Transport type (To service):* Private Car
 - Travel time (To service): 20 minutes
 - o Distance (To service): 12 km
 - Transport cost (To service): \$0 for the 'out' cost (to indicate no parking or toll fares)
 - **Travel from** the appointment:
 - Transport type (From service): Train
 - o *Travel time* (From service): 40 minutes
 - o Distance (From service): Not required for train travel, so leave blank
 - o **Transport cost** (From service): Tick the "Part of a travel pass" option

D1 – Appointments and services

С	Did you travel for this service?	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Transport cost
	Yes 🗸	To service: Car	0 0 : 2 0 h h m m	12 km	\$ total OR
reco	Yes, but it's orded elsewhere	My transport to ar Return by: Train	ond from this service $ \begin{array}{c c} OR \\ \hline 0 & 0 \\ h & h & m & m \end{array} $	is the same	\$ 0 out, and \$ back OR Part of a travel pass*



- 3. The public transport **travel pass**:
 - The travel pass is recorded in **Section A Memberships, subscriptions and multi-day travel cards**
 - Membership start date: "Active at the start of the Cost Diary" (you've been buying this pass for years)
 - Membership type: Public transport pass
 - *Membership cost*: \$90 a fortnight (in real life, you pay \$180 every 28 days, but as there is no '28 day' option, \$90 a fortnight calculates to the same cost).
 - Do you travel for this membership?: "Yes, but it's recorded elsewhere"

Section A – Memberships, subscriptions and multi-day travel cards

Membership start date	Membership type	Membership cost	Do you travel for this membership?	Transport frequency
/ / 2024 OR Active at the start of the Cost Diary	Public transport pass - Myki Pass (Zone 1 + 2)	\$ 90 every fortnight month	Yes Yes, but it's recorded elsewhere No	times a fortnight month year

Other valid options for this scenario:

- 1. The transport details could easily be recorded elsewhere in the Diary (e.g. with another MS related service, or as a stand-alone travel entry in D3 Additional Transport). In this case, in the "Did you travel for this service?" column related to the massage, tick "Yes, but it's recorded elsewhere".
- 2. There are multiple ways the travel pass cost of \$180 every 28 days can be recorded. We chose \$90 a fortnight, but \$45 a week or \$180 a month (as an approximation) are equally valid.

Details not to record from this scenario:

- 1. The "no cost" travel around the appointment i.e. any walking to and from the car, train, or around the massage location.
- 2. Any petrol costs for the car ride these are calculated using the travel distance you've recorded.
- 3. Any "waiting" times, including waiting for the trains to arrive, and waiting to go in for the massage itself.
- 4. The non-MS related purchases i.e. the coffee.

2.2.4.3 Example: An MS related trip using different transport types and multiple travel legs (e.g. "park and ride")

Most Saturdays you use your local "park and ride" facilities to get to and from your gym, where you attend a class and use the pool as part of your exercise routine.

It takes you around **7 minutes** to **drive** the **4 km** to get to where you park, but luckily there are **no associated parking fees**.

The **train** trip to and from the gym takes **around 15 minutes** each way, and you just buy a **return ticket** on the day that **costs \$5**.

Occasionally you decide not to go to the gym, as you don't feel up to it or other things come up. Other weeks you may go to the gym, but don't always go straight home afterwards, as you decide to visit friends, or need to do some shopping.

MS related costs to record:

- 1. The **gym** entry for class and pool use:
 - The time you spend at the gym may not be directly related to your MS, but can be seen to increase your overall health and therefore, indirectly help your MS.
 - Even though you may miss some Saturdays, this is a regular part of your routine, so to cut down individual entries, you should use Section A – Regular services and appointments.
- 2. The **car travel** required to get to and from the train station:
 - The (regular) car travel can be recorded along with the gym details in **Section A Regular services and appointments**.
 - Travel frequency: 1 time(s) a week
 - As the same travel route is generally used out and back, you may use the "My
 journey to and from this service was the same" checkbox.
 - *Travel time*: **7 minutes** (noting the exact travel time will likely vary slightly each time)
 - Distance: 4 km
 - **Transport cost** (total): **\$0** (there are no parking fees or tolls, and petrol and other running costs are calculated from the travel distance)

Section A – Regular services and appointments

Transport frequency	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Transport cost	Membership end date	
₩eek	To service:		4 km	\$ <u>0</u> total	/ / 2024	
1 times a Fortnight Month	My transport to and fro	m this service is the sar	ne	\$ out, and \$ back	OR 6	6
Year	Return by:	h h m m	km	OR Part of a travel pass*	Still active at the end of the Cost Diary	



- 3. The **train travel** required to get to and from the gym itself:
 - The (regular) train travel part of the journey is recorded in Section A Regular transport.
 - As the same travel route is used out and back, you may use the "My journey to and from this service was the same" checkbox.
 - Regular transport start date: "Active at the start of the Cost Diary" (The same start date as the gym membership).
 - Reason for regular transport: "Gym"
 - Travel frequency: 1 time(s) a week
 - *Travel time:* **15 minutes** (the exact travel time will likely vary slightly each time)
 - Distance: Not required for train travel, so leave blank
 - Transport cost (total): \$5

Section A – Regular transport

Regular transport start date	Reason for regular transport	Travel frequpency	Transport type	Travel time	Distance (private car travel only)	Transport cost	Regular transport end date
/ / 2024 OR Active at the start of the Cost Diary	Gym Recorded in Memberships #6	week times a fortnight month		is the same as my out OR journey OR h h m m	km tbound journey km	\$ total OR \$ out, and \$ back OR Part of a travel pass*	//2024 OR Still active at the end of the Cost Diary

Other valid options for this scenario:

As we will be calculating the total travel time for each mode of transport anyway, you are welcome to combine your travel details into one entry.

In the above scenario, this would mean combining time (and distance) out and back for each travel mode into one line:

- Car travel: Time = 14 minutes (7 minutes each way); Distance = 8 km (4 km each way)
- Train travel: Time = 30 minutes (15 minutes each way)

Section A – Regular services and appointments

1 times a fortnight My transport to and from this service is the same out, and month OR Still active at COR	Transport free	quency Transport type	Travel time	Distance	Transport cost	Membership end da	ite
times a out, and out, and out, and out, and back or out and	√	week Car	0 0 . 1 4	8 km		/ /2024	
Still active at —	1 times a	month My transport to a		same	<u> </u>	<u>OR</u>	6
Train O O : 3 O Part of a the end of the Cost Diary] Year	0 0 : 3 0	km	Part of a	the end of the	

Details *not* to record or alter from this scenario:

- 1. The "no cost" travel i.e. any walking to and from the car or train.
- 2. Any petrol costs these are calculated from the travel distance you've recorded.
- 3. Any "waiting" times, including waiting for the trains to arrive.
- 4. Any once off or minor alterations to your plans (i.e. the missed weeks at the gym, the detours to visit friends or shop, and any other once off delays or changes).

2.2.4.4 Example: An MS related trip with multiple stops

You've made an **appointment** with your neurologist, and it takes **25 minutes** to **drive** the **16 km** from your work to the practise. The neurologist wants you to get a **JCV blood test**, and you decide you may as well get it done now as you have time.

The nearest pathology is **5 km** away, and it takes **10 minutes** to **drive** there. You also need to pay **\$10 in parking** as there is no free parking close by.

After getting the blood test the final 17 km trip home takes 30 minutes.

MS related costs to record:

- 1. The neurologist appointment:
 - The neurologist appointment should be recorded in **D1 Appointments and services**.
- 2. The **blood test**:
 - The JCV blood test should be recorded in **D2 Medical tests and scans.**
- 3. The **car travel** required to get to the appointment, the test, and then back home: As long as the total distance, time and costs add up, there are several ways to record transport in this case, and other valid options are described below. Here, we use the transport section of a service entry for two legs, and standalone transport for the third.
 - Leg 1 (drive from work to the neurologist: 25 min; 16 km) and Leg 2 (neurologist to pathology: 10 min; 5 km; \$10 parking): recorded as the transport *To service* and *From service* respectively with the entry of the neurologist appointment in *D1 Appointments and services*.

D1 – Appointments and services

Did you travel for this service?	Transport type	Travel time	Distance	Transport cost
Yes 🗸	To service: Car	0 0 : 2 5 h h m m	16 km	\$total
Yes, but it's recorded elsewhere	My transport to and	from this service is t \underline{OR}	he same	\$ 0 out, and 5 back
No	Return by: Car	0 0 : 1 0 h h m m	5 km	OR Part of a travel pass*

• **Leg 3** (the 30 min, 17 km drive home) is recorded by itself in *D3 – Additional transport D3 – Additional transport*

	Date	Travel reason	Transport type	One-way travel time	One-way distance	Cost
1	19 /4 /2024	Final trip home after neurologist		0 0 : 3 0 h h m m	17 km	\$ 0 trip total OR
	, ,	and pathology (other legs in D1 #1)	_	is trip with these one-v Two legs (o	vay details: ut and back)	Part of a travel pass*



Note: you should also tick the "Yes, but it's recorded elsewhere" for the travel in the blood test entry in D2 – Medical tests and scans:

D2 – Medical tests and scans

Date	Test or scan type	Did you travel for this test?	
		Yes	
19 / 4 /2024	Blood test (JCV)	Yes, but it's recorded elsewhere	
		No 🗌	

Other valid options for this scenario:

As long as the total distance and time taken for all your travel legs add up to the actual combined total, there are several ways to record the trips above, including:

- 1. Recording details in the same manner as above, but with legs 1 and 2 of the trip recorded in D2 Medical tests and scans with the blood test, instead of the neurologist appointment. Note: in this case, the neurologist appointment would have the tick for "Yes, but it's recorded elsewhere" for the travel. Leg 3 is still recorded in D3 Additional transport.
- 2. Tick the "Yes, but it's recorded elsewhere" for travel for both the neurologist appointment (in D1) and the blood test (in D2), then recording all 3 legs as separate, "One leg only" entries in D3 Additional transport.
- 3. Tick the "Yes, but it's recorded elsewhere" for travel for both the neurologist appointment (in D1) and the blood test (in D2), then combine the travel distance and time into a single "One leg only" entry in D3 Additional transport. Noting here, the total travel time is 1 hour and 5 minutes (25 min + 10 min + 30 min) and the total distance is 38 km (16 km + 5 km + 17 km).

D3 – Additional transport

	Date	Travel reason	Transport type	One-way travel time	One-way distance	Cost
1	19 / 4 / 2024	Neurologist appointment (D1 #1) and		0 1 : 0 5 h h m m	38 km	\$ 10 trip total OR
	10 / 4 / 2021	pathology Test (D2 #1)	Number of legs for th One leg only	is trip with these one-wa		Part of a travel pass*

<u>Details not to record from this scenario:</u>

- 1. The "no cost" travel i.e. any walking to and from the car.
- 2. Any petrol costs these are calculated from the travel distance you've recorded.
- 3. Any "waiting" times, such as waiting before the appointment or blood test.
- 4. The initial drive to work (<u>unless</u> MS affects your travel options see *2.2.1- Which trips you need to record*).

2.2.4.5 Example: A trip with multiple stops, but some stops are <u>not</u> related to MS

You've made an **appointment** with your neurologist, and from your work it takes **25 minutes** to **drive** the **15 km** to the practise. Afterwards, you **drive 5 km** to a shopping centre to do some (**non-MS related**) clothes **shopping**, and it takes **10 minutes** to get there. You also need to pay \$10 in parking at the centre. When you're finished, the final **17km** trip home takes **30 minutes**.

MS related costs to record:

- 1. The neurologist appointment:
 - The neurologist appointment should be recorded in D1 Appointments and services
- 2. The recorded **car travel** should just approximate the transport as if you didn't do the non-MS related stops (i.e. the shopping leg). For example, using Google Maps or similar to give you the rough estimate of the journey length (and distance) if you went straight from the neurologist home:
 - Leg 1 (the 25 min, 15km drive from work to the neurologist) is recorded as the 'to service' transport with the entry of the neurologist appointment in D1 Appointments and services.
 - Leg 2 (the 'imaginary' trip straight home from the neurologist): Google Maps indicates a trip from the neurologist straight back home would be a 13 km trip and take around 20 minutes. This can be used as your 'from service' transport with the same neurologist appointment entry in D1 Appointments and services.

D1 – Appointments and services

Do you travel for this service?	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Transport cost	
Yes Yes, but it's recorded elsewhere	To service: Car My transport to an Return by: Car	0 0 : 2 5 h h m m nd from this service OR 0 0 : 2 0 h h m m	15 km sis the same	\$ 0 total OR \$ out, and back OR Part of a travel pass*	1



Other valid options for this scenario:

We do not need exact details for your transport, so it would be perfectly valid in this scenario to just estimate your travel. For example, you know the details from work to the neurologist (25 minutes and 15 km), and you also know the neurologist's practise has taken you around 20 minutes in the past from home, so you'd guess it would be around 10 km.

In this case, you can either enter the details as separate 'to' and 'from' entries as above, or as it is an estimate anyway, just take a rough average and use the "My transport to and from this service is the same".

D1 – Appointments and services

Do you travel for this service?	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Transport cost	
Yes Yes, but it's recorded elsewhere No	Car Wy transport to an Return by:	o o : 2 3 h h m m and from this service OR h h m m	13 km is the same	\$ 0 total OR \$ out, and \$ back OR Part of a travel pass*	1

Details *not* to record from this scenario:

- 1. The initial drive to work and the drive for the (non-MS related) shopping trip (unless MS affects your travel options see 2.2.1 Which trips you need to record).
- 2. The parking cost for the shopping trip (as the shop was not related to MS).
- 3. Any "no cost" travel i.e. any walking to and from the car.
- 4. Any petrol costs these are calculated from the travel distance you've recorded.
- 5. Any "waiting" time before the neurologist's appointment.

2.2.4.6 Example: Transport using a public transport pass

MS affects the distance you are able to walk from time to time, so you have to plan your weekly travel to make sure you can still get to where you need to be on those days where longer distances leave you struggling.

Your general weekly routine involves:

- Two days where it's your turn to drop off and pick up the kids from school. These days you take the car and pay \$50 a week for parking close to work. It takes 15 minutes to get to school, then a further 20 minutes to get to work, with the full trip around 16 km. You generally take the same route home, with the same trip time.
- For the other **three workdays**, you catch a **bus** as there are bus stops close enough to both home and your work.
- For your other general travel, you tend to use a combination of the bus and the train, so you buy a **28-day public transport** pass (which costs **\$178.08 every 4 weeks**), as it ends up cheaper than paying for individual trips.
- In the last few weeks, you've used the **public transport pass** for your usual **work bus travel**, as well as a **Saturday 15-minute** (each way) trip on the **train** to the local shopping centre to get some **MS related supplies** (your medication and new inner soles for your shoes).

MS related costs to record:

- 1. The MS related purchases:
 - Medication should be recorded in C1 Medications and supplements.
 - Inner soles should be recorded in C2 New item purchases and equipment hiring.
- 2. The 28-day public transport pass:
 - Record the public transport pass cost in Section A Memberships, subscriptions and travel passes.
 - In the **Do you travel for this membership?** column tick "Yes, but it's recorded elsewhere".
 - Record each trip for MS related purposes that uses this public transport pass in its appropriate transport section with the "Part of a travel pass" ticked in the Transport cost column.

Section A – Memberships, subscriptions and travel passes

Membership start date	Membership type	Membership cost	Do you travel for this membership?
/ / 2024 OR Active at the start of the Cost Diary	Public transport pass Myki Pass (Zone 1 + 2)	\$ 90 every fortnight month year	Yes Yes, but it's recorded elsewhere No

^{*}Note: if MS <u>doesn't</u> impact how you get around, still record the <u>full cost</u> of a transport pass in Section A, even if you only use it for one or two MS related trips.



3. In this example, we have indicated you have to plan your travel to cater for the 'not-so-good' MS days, so you need to **record** <u>all</u> **your travel**:

Work related travel:

- Both the work-related **car** and **bus** travel should be recorded in **Section A Regular transport**, but as separate entries.
- The **bus** travel should use the "Part of a travel pass" checkbox for the Transport cost.
- Note the cost for the car is recorded as \$25 for each trip (\$50 a week for 2 uses).

Section A – Regular transport

Regular transport start date	Reason for regular transport	Travel frequency	Transport type (private car, taxi, public transport)	Travel time	Distance (private car travel only)	Transport cost	Regular transport end date
/ / 2024 OR Active at the start of the Cost Diary	Work	week times a fortnight month	Outbound: Bus My return journey This is a single leg Return by:	o o constant of the same as my out on the same as my out on the same of the same as my out on the same of the same as my out on the same as my out on the same as my out on the same as my out of the	KIII	\$total OR \$out, and \$back OR Part of a travel pass*	/ / 2024 OR Still active at the end of the Cost Diary
/ / 2024 OR Active at the start of the Cost Diary	Work	week times a fortnight month	Outbound: Car My return journey i This is a single leg journey.	<u>OR</u>	10 km bound journey	\$ 25 total OR OR Out, and Dack OR Part of a travel pass*	//2024 OR Still active at the end of the Cost Diary

Non-work related travel:

• The **train** ride for the shopping trip should be recorded in **D3 – Additional transport** with the "**Part of a travel pass**" checkbox ticked for the **Transport cost**.

D3 – Additional transport

	Date	Travel reason	Transport type	One-way travel time	One-way distance	Cost
1	10 / 5 / 2024	Shopping trip for MS supplies	Train	0 0 : 1 5 h h m m	km	trip total OR
		(C1 #6 and C2 #3)		is trip with these one-wa	Part of a travel pass*	

Details *not* to record from this scenario:

- 1. The "no cost" travel i.e. any walking to and from the car or public transport stops.
- 2. Any time waiting for public transport to arrive at the station or bus stop.
- 3. Any petrol costs these are calculated from the travel distance you've recorded.
- 4. Any other 'non-MS' related purchases made on the shopping trip.
- 5. Any minor variations to your regular work travel (e.g. days off sick, annual leave, unusual days where you may take the car instead of the bus, vice versa, or some alternative mode of transport as a once off, days with unusual traffic delays etc.)

2.2.4.7 Example: Recording frequent transport when MS limits your travel options

MS doesn't always limit how far you can walk, or what mode of transport you use, but it does often enough that any future travel plans you make have to assume that you'll be having a 'not-so-good' day, just in case. This generally means taking your car if there's not public transport stops close enough, or worst case, organising a lift or Uber if parking is also going to be restrictive.

Between work, your kids' activities, appointments and shopping, you also travel a lot, and it's a mix between your car, public transport, and the occasional Uber ride.

In general, in a **normal school week**, you'll take the kids to school in the **car** (around **10 minutes** for the **5 km**), then drive to your local "park and ride" to catch the **train** to work (normally a **25-minute** trip, and it works out as **\$10** a day return). You then **reverse the routine** again in the afternoon, catching the **train** back to your **car**, so you can pick the kids up from school. After school is all over the place though. With travel around to various activities, **some days may be an hour** in the car after school covering **35 km** or so, and **other days** you get to go straight home, and it's only **10 minutes** to go **5 km**.

Weekends is filled with more kids' activities (in the car), and you'll also duck out to the gym at some point. On top of that, you also have various social outings that may be a mix of car, Uber and public transport, depending on what it is and when. **No two weekends are the same**.

<u>Recording your MS related travel:</u> In this scenario, the main thing to remember is that **estimates are good enough** for us, so take whatever approach you feel comfortable with. If you wish to record each trip individually, you are welcome to, but to save yourself time (and a lot of data entry), we recommend one of the following 'summarised' approaches:

- Option 1: Creating entries in Section A Regular Transport that cover your most routine travel, and then adding any unusual or additional trips individually as they occur in D3 Additional transport. Best suited to those with fairly predictable travel routines that may also include a few unplanned trips here and there.
- Option 2: Keeping a separate detailed log of your travel, then transferring summary entries of your total travel for each mode of transport every few weeks or months into D3 Additional transport. Best for those who don't like to estimate, and feel more comfortable keeping track of their day to day travel.
- Option 3: Using a 'best guess' approach, which combines Option 1 and Option 2, to create a summary of your transport over the last few weeks or so using Section A Regular Transport to create average usage entries for each mode of transport. Best suited to those who don't necessarily have 'standard' travel, and don't feel they would consistently keep a log, but feel comfortable looking back over a period of time (fortnightly or monthly) and creating an entry that reflects an appropriate estimate of their transport over that time.

An example of how to record each of these options for the scenario above is outlined over the next few pages.



<u>Option 1:</u> Recording your most common/routine travel in Section A (Regular Costs), and then recording any additional, one-off trips in D3 – Additional transport.

Remembering we only need a rough average, and it won't matter if details such as travel time or frequency change a little from week to week. For this scenario, record as approximate averages in separate entries in *Section A – Regular transport*:

- Regular weekday car travel for work and school pick-up/activities.
- Regular train travel for work.
- Regular weekend car travel for sport.

Section A – Regular transport

Transport start date	Reason	Travel frequency	Transport type	Travel time	Distance	Transport cost	Transport end date
/ / 2024 OR Active at the start of the Cost Diary	Work (approx.)	week times a fortnight month	Train My return journey This is a single leg Return by:	<u>OR</u>		\$ 10 total OR OR out, and back OR Part of a travel pass*	//2024 OR Still active at the end of the Cost Diary
OR Active at the	School drop off / pick up and activities (approx)	week times a fortnight month	Outbound: Car My return journey in this is a single leg just a second of the second	$ \begin{array}{c c} \hline 0 & 0 \\ h & h \end{array} $ Is the same as my out $ \underline{OR} $	28 km bound journey	\$ 0 total OR \$ out, and \$ back OR Part of a travel pass*	// 2024 OR Still active at the end of the Cost Diary
/ / 2024 OR Active at the start of the Cost Diary	Weekend kids' sport	week times a fortnight month	Outbound: Car My return journey This is a single leg Return by:	<u>OR</u>	30 km tbound journey	\$ 10 total OR \$ out, and \$ back OR Part of a travel pass*	// 2024 OR Still active at the end of the Cost Diary

 Record any trips you make outside this 'regular' travel individually as they occur, for example the family trip to the movies in the car, and the Uber to your (non-MS) specialist appointment (D3 – Additional Transport).

D3 – Additional Transport

	Date	Travel reason	Transport type	One-way travel time One-w	ay distance	Cost
1	1 / 5 / 2024	Social (trip to movies)	Car	0 0 : 2 0 h h m m	10 km	\$ 20 trip total OR
			Number of legs for this One leg only	trip with these one-way details: Two legs (out and back)		Part of a travel pass*
2	11 / 5 /2024	(Non-MS)	Uber	0 0 : 2 5 h h m m	13 km	\$ 50 trip total OR
_	•	medical appointment	Number of legs for this One leg only	trip with these one-way details: Two legs (out and back)		Part of a travel pass*

<u>Option 2:</u> Keeping a transport log for each mode of transport, and transferring summary entries to the Cost Diary

This method would involve keeping a logbook of your usage, then just transferring the totals (by transport type) into **D3 – Additional transport** at the end of the month.

For example, you could keep a notebook in the car and record your odometer reading on day 1, then record the length of time you're in the car for each trip you make (and any parking paid). At the end of the month, take the odometer reading again to get the total distance you've travelled, and add up all the trips for the total time, then record this all as a single entry in D3 – Additional transport.

D3 – Additional transport

Date Travel reason		Transport type	One-way travel time	One-way distance	Cost	
1	/ 5/2024	All my car transport for	Car	2 1 : 0 0 h h m m	640 km	\$ 130 trip total OR
		May	Number of legs for th One leg only	is trip with these one-wa	•	Part of a travel pass*

<u>Note:</u> Using this method, you would always tick the "My transport is recorded elsewhere" for any MS related service entries.

Option 3: Using a 'best guess' approximation of your usage

This is a combination of knowing your routine, and being reasonably confident in your estimations to record bulk details for each of your transport types based on what is 'average' for you.

For example, you can confidently estimate:

- You average 250 km in the car each week and would spend somewhere between 4 to 4 and a half hours doing that travel. Generally, you pay \$15 or so every few weeks in parking (which works out as the equivalent of around \$5 a week).
- You'd spend around \$20 on a two or three 20 30 minute train trips each week (spending approximately a combined 45 to 60 minutes on the train each week).

 Note: This information is combined as a total 'one trip a week' approximation in the below example.
- You would normally catch an Uber maybe 3 or 4 times a month, and it's generally around \$40 and 20-minutes each time.

It would be OK for our purposes to use these estimates as your 'total' travel for the full *Cost Diary* period in *Section A – Regular transport*. You would then also need to tick the "*My transport is recorded elsewhere*" for any MS related service entries.

Section A – Regular transport

Section A – Regular transport								
Regular transport start date	Reason for regular transport	Travel frequency	Transport type (private car, taxi, public transport)	Travel time	Distance (private car travel only)	Transport cost	Regular transport end date	
/ / 2024 OR Active at the start of the Cost Diary	My approx. weekly car travel	week times a fortnight month	Outbound: Car My return journey This is a single leg grade. Return by:	is the same as my ou OR journey OR h h m m	250 km	\$ 5 total OR \$ out, and \$ back OR Part of a travel pass*	// 2024 OR Still active at the end of the Cost Diary	
/ / 2024 OR Active at the start of the Cost Diary	My approx. weekly train travel	week times a fortnight month	Outbound: Train My return journey i ✓ This is a single leg journey.	<u>OR</u>	km tbound journey km	\$ 20 total OR OR out, and back OR Part of a travel pass*	// 2024 OR Still active at the end of the Cost Diary	
/ / 2024 OR Active at the start of the Cost Diary	My approx. Uber usage a month	week times a fortnight month	Outbound: Uber My return journey This is a single leg grant single leg	is the same as my or OR journey OR h h m m	km utbound journey km	\$ 40 total OR \$ out, and \$ back OR Part of a travel pass*	// 2024 OR Still active at the end of the Cost Diary	

2.3 SECTION A: YOUR REGULAR COSTS

This section is for any costs you have that are predictable and form part of your regular routine. In other words, if you use a service that you could fairly confidently put the upcoming usage or payments at known, regular intervals in your calendar in advance, then they probably belong in this section.

Using this section will mean you don't have to then record every individual visit or payment for services you use frequently. Examples may include regular home help (such as cleaning, gardening, or meal delivery), gym memberships, subscription-based items, and travel to get to work. Even slightly irregular services may be included and missed sessions do not have to be adjusted for, as long as your overall usage recorded over the 6-month period is a good representation of what you would generally use had life not intervened.

2.3.1 Your regular costs – detailed information about what you need to enter for all regular costs

We will be calculating the total cost over 6 months for each of the regular services you record in this section, and as such, we need to know how long you were receiving or paying for each service during this time using the Start and End date columns for all regular services as described below.

2.3.1.1 Your regular cost tables: **Start date**

An exact start date is only required if you happen to start a **new** regular service during the *Cost Diary* period, and the date should reflect the **first day you made a payment or the first day you received the service** (whichever comes first) and should be in the format D/M/YYYY (e.g. 5/6/2024 for the 5th of June 2024). We will then calculate the cost for the rest of the *Cost Diary* period from this date.

For any regular costs that you were **already using at the start of the** *Cost Diary*, we don't need to know an exact date that the cost started, as we will only be calculating the cost you have incurred over the 6-months itself. In this case, tick the "*Active at the start of the Cost Diary*" box to let us know the cost was already in place when you began.

2.3.1.2 Your regular cost tables: **End date**

The end date for this section should ideally be left blank until the end of the *Cost Diary* period, as even regular services you don't think will change may end up with an unexpected price increase that requires a new entry.

Before you send your *Cost Diary* back to us, we will be sending you a checklist that will include going through all your regular costs and confirming the ones that are still ongoing by ticking the "Still active at the end of the Cost Diary" checkbox.

If you do stop using a service, or the cost changes (for example, the frequency or price of the service), you will need to enter an end date using the format D/M/YYYY (e.g. 5/6/2024 for the 5th of June 2024). This should either be the day the service or subscription expired, or the last day you used or received the service at the recorded cost, whichever date comes last.

2.3.2 Missed sessions or adjustments to your regular costs

We recognise that there are likely to be times when costs recorded in this section don't 100% reflect real life; your cleaner may be sick one week and you don't get a replacement, or you take a week off work and therefore don't use the work travel you've recorded. These minor variations require no changes or comments, as long as you are expecting to resume using the same frequency and cost within the next week or two.

If, however, the frequency you use the service, or the cost of that service is changing permanently or for an extended period of time (more than two weeks), then we ask you to record this change in the *Cost Diary*. To do this, simply add an *End date* for your existing entry that best reflects the last day you could use the service with the old frequency and cost. Then add a new entry with the *Start date* reflecting the first day you used the service or made a payment with the new frequency and cost.

2.3.2.1 Example: Adjustment to a regular cost that has had a permanent change

Twice a week, you catch the **bus** to and from work as it is the only affordable option that gets you within the close walking distance you need to prevent your MS symptoms from impacting the day. Unfortunately, the bus company is putting up its prices at the start of April, so it is now going to cost you **\$12** for the return trip, instead of **\$10**. The last time you catch the bus at the **old price** was on Thursday the **29**th of March, and the next trip on **Tuesday 2**nd of April is when the **new price** kicks in.

MS related costs to record:

- Record the regular **bus travel** at the original price in **Section A Regular transport** with an **end date** of **29**th **of March** (the last time you caught the bus at this price).
- Record the regular bus travel at the new price as a separate entry in the same section (Section A – Regular transport) with a start date of 2nd of April (the first time you catch the bus at the new price).

Section A – Regular transport

Regular transport start date	Reason for regular transport	Travel frequency	Transport type (private car, taxi, public transport)	Travel time	Distance (private car travel only)	Transport cost	Regular transport end date
/ / 2024 OR Active at the start of the Cost Diary	Work	week times a fortnight Month	Outbound: Bus My return journey This is a single leg Return by:	is the same as my out OR OR OR h h m m	km itbound journey km	OR \$out, and \$back OR	OR Still active at the end of the Cost Diary
2 / 4 /2024 OR Active at the start of the Cost Diary	Work	week times a fortnight Month	Outbound: Bus ✓ My return journey i This is a single leg journey.	<u>OR</u>	km tbound journey km	\$ 12 total OR \$ out, and \$ back OR Part of a travel pass*	//2024 OR Still active at the end of the Cost Diary

2.3.3 Frequent, but not-quite-so-regular costs and the Your Regular Costs section

The advantage of the regular cost section is that it reduces the amount of entry you need to do for services you use frequently. In general, we are only interested in the overall cost of your services during the 6-months of the *Cost Diary*, and it doesn't matter exactly *when* these costs occurred. Therefore, you are welcome to use the *Regular Costs* sections to create a summary of services you use frequently, even if they are a bit irregular, as long as the calculated total for the 6-months roughly matches your actual usage.

2.3.3.1 Example: Options for recording a frequent, but not necessarily regular, cost

You often see your **physiotherapist**, but as it is only on an 'as needed' basis, this can **vary from once a week, to once a month** depending on how you're feeling.

Even with the variance in how often you see them, you **always** have your appointments on a Friday, and you take your **car**. Sometimes you may also slot in other tasks or visits on either side of the appointment.

MS related costs to record:

There are multiple ways to record this. Please use an option that you are most comfortable with. The below examples include:

- Option 1: Record each individual visit as it occurs in D1 Appointments and other services.
- Option 2: Have a 'master' entry in Section A Regular services and appointments to keep a tally. Then enter the exact total at the end of the 6-month period.
- Option 3: Use Section A Regular services and appointments to record entries with frequencies that closely reflect your usage, even if it's not exact.

Option 1: Recording each visit individually

For those who tend to record costs when they happen, it is likely easiest for you to record each individual visit as it occurs:

- Record each physiotherapy session as a separate entry in D1 Appointments and other services.
- Record the associated car travel in the transport section with each physiotherapy entry in D1 – Appointments and other services.

D1 – Appointments and other services

Date	Service type	Length of appointment	Type of appointment
5 / 4 / 2024	Physiotherapy	0 0 : 3 0 h h m m	Face-to-face Telehealth
26 / 4 / 2024	Physiotherapy	0 0 : 3 0 h h m m	Face-to-face Telehealth
24 / 5 / 2024	Physiotherapy	0 0 : 3 0 h h m m	Face-to-face Telehealth

<u>Option 2:</u> Keeping a tally of your appointments, then recording one summary entry
For those who know they may be using the same service frequently, but don't necessarily know exactly how often, it may be easier to enter an 'incomplete' entry in Section A – Regular services and appointments, and just keep a tally next to the entry. At the end of the 6 months, you can then enter the final 'frequency' details to match your actual usage:

• Record the physiotherapy service in Section A – Regular services and appointments, leaving the Service start date, Service end date and Usual frequency of service or appointment columns blank. Using the space in the Type of service or appointment column, put a tally line each time you have an appointment.

Section A – Regular services and appointments

	Service start date	Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment	
1	/ /2024 OR Active at the start of the Cost Diary	Physiotherapy Tally:	0 0 : 3 0 h h m m	week times a fortnight month OR total over 6-months	

• At the **end of the** *Cost Diary* period, **add up your tallied amount** and use the "*total over 6-months*" option in the *Usual length of service or appointment* to record your total usage over the 6-month period.

Section A – Regular services and appointments

	Service start date	Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment	
	/ /2024	Physiotherapy		week times a fortnight	
1	OR Active at the start of the Cost Diary	<i>Tally:</i> ++++	0 0 : 3 0 h h m m	month	
	of the cost biary			total over 6-months	

Option 3: Recording an approximate frequency that is roughly equivalent to your usage

The final option, which can have multiple different versions, is to create one or more regular service entries that come out as roughly the same as your actual usage.

Using the above example, if you saw the physio almost every week during the first 3 months of the *Cost Diary* (but you missed a few along the way), and then you switched to once a month-ish for the final 3 months (13 visits in total over the 6-months), you would be welcome to record this in *Section A – Regular services and appointments* as:

- 1. two separate entries with the two 'frequencies' (one for the first 3 months, and another for the final 3), or
- 2. one approximate usage that covers the full six months

You'll note neither of these options give the 'exact' number of visits, but they are close enough and save you having to go back and count exactly how many visits you had if you haven't necessarily kept a record.

- 1) Two separate approximate entries covering the different frequencies:
 - * Entry 1 would be end dated 15/7/2024

Section A – Regular services and appointments

Service start date		Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment	
1	/ / 2024 OR Active at the start of the Cost Diary	Physiotherapy	0 0 : 3 0 h h m m	week times a fortnight month OR total over 6-months	
2	16 / 7 / 2024 OR Active at the start of the Cost Diary	Physiotherapy	0 0 : 3 0 h h m m	week 1 times a fortnight month OR total over 6-months	

2) One approximate usage that covers the full 6-months:

Section A – Regular services and appointments

Service start date		Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment	
	/ / 2024 OR Active at the start of the Cost Diary	Physiotherapy	0 0 : 3 0 h h m m	week times a fortnight month OR total over 6-months	

2.3.4 Your Regular Costs: NDIS and My Aged Care package information

While there are many different forms of funding, discounts and reimbursements available, we are only collecting details of National Disability Insurance Scheme (NDIS) and *My Aged Care* packages in the *Cost Diary* to provide in-depth supporting data needed for our upcoming study investigating how well the NDIS is really supporting people with MS.

Please also note that we collected information on your concession and funding details in the *Economic Impact Study - Baseline Survey* that you completed prior to the *Cost Diary*. As long as you remember to record all your MS related purchases and service usage in the *Cost Diary* and how much you paid yourself, we have a good idea of how much other sources, such as the government or other funding bodies, have contributed.

2.3.4.1 NDIS and *My Aged Care* package information – detailed information about what you need to enter

For those who have NDIS or *My Aged Care*, the package information we need is separated into two entry tables:

- 1. The package amount table: is for your approved annual package amount in dollars, and the date this amount was approved.
- 2. <u>The package items table:</u> is to list which service and item entries recorded elsewhere in the *Cost Diary* were paid for by your NDIS or *My Aged Care* package.

The data entry requirements for each table are described below.

2.3.4.1.1 NDIS and My Aged Care: Package amount table - Start date

This column is for the date your NDIS or *My Aged Care* was officially approved, and you could start making purchases under that package.

See 2.3.1.1 - Your regular cost tables: Start date for more information on start dates in Section A of the Cost Diary.

2.3.4.1.2 NDIS and My Aged Care: Package amount table - Package type

Select the type of package you receive by ticking the appropriate checkbox:

- 1. **NDIS** for National Disability Insurance Scheme packages.
- 2. **My Aged Care** for My Aged Care packages.

2.3.4.1.3 NDIS and My Aged Care: Package amount table - Annual package amount

This column is for you to enter the **total** amount (to the nearest dollar) of the funding you receive for your package. We **do not** need a breakdown of any sub-categories within the overall package but we will ask you to identify any services or items you receive during the 6-months of the *Cost Diary* as part of your package in the "package items" table.

If your package amount changes (for the same type of package), or you transfer from NDIS to *My Aged Care* during the 6-months, create a new entry in the table with the *End date* of the previous package the day before the new package came into effect (i.e. the *Start date* of the new package).

2.3.4.1.4 NDIS and My Aged Care: Package amount table - End date column

This column is for the last date you could make purchases under your old NDIS or *My Aged Care* package, which will generally coincide with the day before your new package details started if you have been approved for a new package.

See 2.3.1.2 - Your regular cost tables: End date for more information on end dates in Section A of the Cost Diary.





2.3.4.1.5 NDIS and My Aged Care: Package items table - Description

This column is for a **one or two key word description of the item** for which you have received funding. It only needs to be very short as it is just a double check to ensure the page and item number you have listed in the associated *Cost Diary page* and *Page entry number* columns correctly match the entry for the intended item.

For example, if you received funding to add handrails to a walk-in shower, the full details for the handrail should be recorded in *Section B – Housing and long-term assets*. To indicate this was paid for by a NDIS or *My Aged Care* package, you would just need to enter "shower renovation" or "handrail" as the description in the *Package items* table in *Section A: NDIS and My Aged Care package information*, along with the corresponding *Section B* entry page and number.

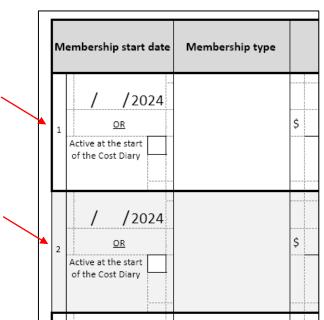
2.3.4.1.6 <u>NDIS and *My Aged Care*</u>: **Package items table - Cost Diary page**This column is to record the corresponding **Cost Diary page number** where you have entered the full details for an item that you have received through NDIS or *My Aged Care* funding.

You will find the page number at the centre bottom of each page in the Cost Diary:



2.3.4.1.7 NDIS and My Aged Care: Package items table - Page entry number

This column is to record the corresponding **record entry number** where you have entered the full details for an item that you have received through NDIS or *My Aged Care* funding. You will find this entry number on the far left of each table throughout the *Cost Diary* (and it is repeated in the far right for entries with associated transport that span two pages).



2.3.4.2 Example: Updating NDIS or My Aged Care package information

You already had an approved \$12,000 per year NDIS package at the start of the *Cost Diary*, but you have just received confirmation of an upgrade to \$26,000 a year commencing on the 13th of June. This is exciting as you'll get a **fortnightly gardener** for 2 hours now, starting on the 1st of July. This is in addition to the **existing 3 hours** of **cleaning and home assistance** you get 2 times a week.

MS related costs to record:

The **initial setup** of your NDIS funding would include:

- 1. Details of the initial funding amount of \$12,000 in Section A: NDIS and My Aged Care in the package information table.
- 2. Full details of the cleaning and home assistance (3 hours; twice a week) recorded in Section A: Your regular services.
- 3. Listing the cleaning and home assistance entry as a NDIS funded service in **Section A: NDIS and My Aged Care** in the **Package items table.** The **Description** is entered as "Home assistance", with the corresponding **Page entry number** as **entry 1** on **page 12** (from Section A: Your regular services).

Section A: NDIS and My Aged Care

Start date	Package type	Annual package amount	End date
/ / 2024 OR Active at the start of the Cost Diary	NDIS: My Aged Care:	\$ 1 2 , 0 0 0 .00	/ / 2024 OR Still active at the end of the Cost Diary

	Description	Cost Diary page	Page entry number
1	Home assistance	12	# 1
2			#

Section A: Your regular services

Section A. Tour regular services						
Service start date	Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment			
/ / 2024 OR Active at the start of the Cost Diary	Home assistance (cleaning, meal preparation)	0 3 : 0 0 h h m m	week times a fortnight month OR total over 6-months	•		





2) When the **upgraded NDIS funding** commences:

- The initial funding entry in the package information table in Section A: NDIS and My Aged Care should have the End date entered as the day before the approval date of the new NDIS package amount (i.e. the 12th of June).
- A new NDIS entry needs to be added in the package information table in Section A: NDIS and My Aged Care that has a Start date as the approval date of the new NDIS package amount (i.e. the 13th of June).
- 3. The new funded gardening service (2 hours per fortnight) should be entered in **Section A: Your regular services**, with a **Start date** matching the first time the gardener does a gardening shift (1st of July).
- 4. Please note that no changes need to be made to the on-going "home assistance" service entry.

Section A: NDIS and My Aged Care package information:

Start date		Package type	Annual package amount End date
	/ / 2024	NDIS: 🗸	12 / 6 / 2024
1	OR Active at the start of the Cost Diary	My Aged Care:	\$ 1 2 , 0 0 0 .00 Still active at the end of the Cost Diary
	13 / 6 / 2024	NDIS: 🗸	/ / 2024
2	OR Active at the start of the Cost Diary	My Aged Care:	\$ 2 6 , 0 0 0 .00 Still active at the end of the Cost Diary

Description		Cost Diary page	Page entry number	
1	Home assistance	12	# 1	
2	Gardening	12	# 2	

Section A: Your regular services

Section A. Your regular services					
	Service start date	Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment	
1	/ / 2024 OR Active at the start of the Cost Diary	Home assistance (cleaning, meal preparation)	0 3 : 0 0 h h m m	week times a fortnight month OR total over 6-months	
2	1 / 7 / 2024 OR Active at the start of the Cost Diary	Gardening	0 2 : 0 0 h h m m	week times a fortnight month OR total over 6-months	

2.3.5 Your Regular Costs: Memberships, subscriptions and multi-day travel cards

Memberships, subscriptions, and multi-day travel cards can be used for any costs where you pay for a service for a set period of time, and you can generally use that service as much as you like over that period of time. They often have 'auto-pay' periods, where you will get charged for the next period of time without having to manually make each payment unless you cancel your membership or subscription in advance. However, this can also include some post-paid services, such as phone or internet packages.

Common examples include gyms and pool memberships, multi-trip travel cards (Myki Pass, Opal, Translink, Metro, Transperth, MyWay), online self-help health subscriptions, monitoring services, or communication service provider contracts.

2.3.5.1 Memberships, subscriptions and multi-day travel cards – detailed information about what you need to enter

For each membership, subscription, or multi-day travel card you have, we need to know a brief description of what it is, how much it costs you, how often you pay this amount (which can also be thought of as how long you get to use the services covered by each payment), and if you have any regular travel associated with the use of the membership or subscription.

As we will be calculating the pro-rata cost you have incurred over the 6-month period, it is important you provide us with start and end dates as accurately as possible for your memberships, subscriptions or travel cards as described below.

2.3.5.1.1 Memberships, subscriptions and multi-day travel cards: Membership start date

This column should reflect the **date you are first able to use the services provided** by your membership, subscription or multi-day travel card. Generally, this will also coincide with the day of payment.

If the membership, subscription or travel card was already active at the start of the *Cost Diary*, (that is, you had a payment for the service prior to the *Cost Diary* start date, which means you would have been able to use the services on the *Cost Diary* start date), just tick the "Active at the start of the Cost Diary" checkbox.

See 2.3.1.1 - Your regular cost tables: Start date for more information on start dates in Section A of the Cost Diary.

2.3.5.1.2 <u>Memberships, subscriptions and multi-day travel cards:</u> **Membership type** This column is the **name or a short description** of the membership, subscription or travel card type. We don't need a long description – just a few key words, such as 'gym – equipment only', 'gym and pool', or 'Calm App', just to ensure we classify the cost correctly.





2.3.5.1.3 Memberships, subscriptions and multi-day travel cards: Membership cost
The membership cost should reflect how much you paid, and how long that payment gives
you access to the associated services. This can include memberships and subscriptions
where you are charged a set amount at regular intervals, such as a monthly fee of \$10.99
charged to your credit card but can also be one-off payments for a set period of time.

For some services, your payment may be required as infrequently as once a year, but we still need this detail to calculate what your equivalent cost would be over 6-months.

Rounding the cost to the nearest dollar is also welcome.

If a **fee change** occurs for one of your memberships or subscriptions during the 6-months, just create a new entry in the table with the *Start Date* corresponding to the first day you have access to the services at the new fee rate. This will most commonly be the day you made the first payment at the new rate.

The entry at the 'old' price should then have an *End date* as the last day you had access to the service at the 'old price', which will generally be the day before the first payment at the new price.

2.3.5.1.4 <u>Memberships, subscriptions and multi-day travel cards:</u> **Do you travel for this membership?**

Some memberships and subscriptions will have **travel associated with the use of that service**. For example, you need to get to the gym or pool in order to use it. If this is the case, <u>and</u> you have **a fairly set routine** for your use of that service, you may record the associated travel in this section.

We don't expect this travel to be a 100% accurate recording of your travel either. It is perfectly OK to say you go to the gym 3 times a week by car, but find you miss a few through illness or other appointments. Similarly, it would be fine if your car broke down and you had to take a taxi for 2 weeks until your car is fixed, or you took slightly different routes each time, depending on what else you needed to do on the day.

However, **if your associated travel is <u>not</u> very predictable**, either in its frequency or transport type, you may want to consider using multiple regular travel entries, or individual travel entries (see 2.2.2 - Where to record your transport and how the cost is calculated).

For multi-day travel cards: do **not** record associated travel with the cost of the card itself (use the "**Yes, but it's recorded elsewhere**"), as we will need to know the details of the other MS related purchase or service you are using that travel card to get to, and this is where the actual travel details should be recorded (see 2.2.4.6 - <u>Example</u>: Transport using a public transport pass).

2.3.5.1.5 <u>Memberships, subscriptions and multi-day travel cards:</u> **Membership end date** This column should reflect the date your membership, subscription, or multi-day travel card **expired** (i.e. the last day you were able to use the service and <u>not</u> the last payment date).

If the membership, subscription or travel card is still active at the end of the *Cost Diary* period, (that is, your most recent payment will cover your use of the associated service for every day up until the last day of the *Cost Diary* or beyond), just tick the "Still active at the end of the Cost Diary" checkbox.

See 2.3.1.2 - Your regular cost tables: End date for more information.

2.3.5.2 Example: An ongoing subscription with a price change

Two of the biggest challenges you face with your MS are fatigue and anxiety.

To help alleviate some of the impact of these symptoms, you **signed up a while ago** to a **yearly \$74.99 "Calm" subscription** that gives you access to anxiety reducing techniques, information, and tools. Halfway through the *Cost Diary* period, your subscription is up for renewal, and there has been a slight **increase** in the **yearly subscription price**, which is **now \$79.99** a **year**. The associated payment appeared on your credit card on the **18**th **of July**.

A friend has also noticed the impact of your fatigue and suggested looking into using one of the **meal packaging services** to try and reduce the burden of the weekday dinners. As a result, you've decided to trial ordering 3 meal preparation kits at **\$90** a week through the Hello Fresh company.

MS related costs to record:

- The original Calm subscription (\$74.99 per year) should be recorded in Section A: Memberships, subscriptions and travel passes, and as you were already using it when the 6-months of the Cost Diary started, it should use the "Active at the start of the Cost Diary" checkbox in the Membership start date.
- On the renewal date of the Calm subscription, the new subscription details (\$79.99 a year) should be recorded as a new entry in Section A: Memberships, subscriptions and travel passes with a Membership start date of the 18th of July.
- The original subscription entry should also now have a Membership end date recorded as 17th of July.
- The Hello Fresh subscription (\$90 a week) can also be recorded in Section A: Memberships, subscriptions and travel passes.

Section A: Memberships, subscriptions and travel passes

Membership start date	Membership type	Membership cost	Do you travel for this membership?	 Membership end date
/ / 2024 OR Active at the start of the Cost Diary	Calm	\$ 75 every fortnight month	Yes, but it's recorded elsewhere	 17 / 7 / 2024 OR Still active at the end of the Cost Diary
2 / 7 / 2024 OR Active at the start of the Cost Diary	Hello Fresh (Meal packages)	\$ 90 every fortnight month	Yes Yes, but it's recorded elsewhere	 / / 2024 OR Still active at the end of the Cost Diary
18 / 7 / 2024 OR Active at the start of the Cost Diary	Calm	\$ 80 every week fortnight month	Yes, but it's recorded elsewhere	 / / 2024 OR Still active at the end of the Cost Diary





2.3.5.3 Example: Memberships where travel is required to use the service

A combination of age and MS symptoms is starting to impact your dexterity and overall flexibility. Your physio has recommended switching out your high intensity sports with more regular, but gentler exercise, and using your creative side to find a new hobby to keep your hands moving.

You've already found a local **gym** that has a pool, exercise bikes and some suitable low intensity classes and you've generally been going **3** or **4** times a week on the way home from work to do various activities. You've also had a **few weeks** where you've been too sore to go or had other things on and have **only been able to go once or twice** in those weeks. You have a direct debit setup for the **fortnightly \$52.85** payments for the membership.

You've also found a council run arts centre that has **fortnightly** informal gatherings on a Saturday **with a local artist**. It's very social, and a lot of fun, but the painting also helps with keeping up your fine motor control. The gatherings themselves are free, but there is a **\$50 a year Art Society membership fee** that helps cover the very basic costs of the gatherings.

MS related costs to record:

- The costs associated with the gym membership (\$52.85 a fortnight) and Art Society membership (\$50 a year) should be recorded in Section A: Memberships, subscriptions and travel passes.
- Any costs incurred for travel to the gym and painting gatherings should also be recorded. This can be done in the same entry as the associated memberships in Section A: Memberships, subscriptions and travel passes.

Section A: Memberships, subscriptions and travel passes

Membership start date	Membership type	Membership cost	Do you travel for this membership?	Transport frequency
/ / 2024 OR Active at the start of the Cost Diary	Gym (equipment, pool and classes)	\$ 53 every fortnight month year	Yes, but it's recorded elsewhere No	week times a fortnight month year
2 / 7 / 2024 OR Active at the start of the Cost Diary	Art society	\$ 50 every fortnight month	Yes, but it's recorded elsewhere	week times a fortnight month year

Other valid options for this scenario:

• If you have **travel** associated with the use of a membership, but you **don't have a regular pattern** for your usage, you may feel more comfortable using the "Yes, but it's recorded elsewhere" checkbox in the Do you travel for this membership column, then recording each individual trip in D3 – Additional transport.

Details not to record from this scenario:

For memberships and subscriptions recorded in this section, you do not have to
enter any other details when you use the associated services. For example, individual
exercise classes you may attend that are part of your membership fee should not be
recorded elsewhere.

2.3.6 Your Regular Costs: Regular services and appointments

Your regular services and appointments are those services you use frequently that are charged on a 'per use' or 'per session' basis. The most common examples are paid home assistance in the form of regular cleaning, gardening, personal assistance, or meal preparation. Other examples can include regular appointments with allied health professionals, such as regular physiotherapy or dry needling, and regular visits to use services such as exercise classes or a pool, where you pay for each individual visit (or a set number of visits).

2.3.6.1 Regular services and appointments – detailed information about what you need to enter

We will be calculating the **total cost** for your service usage **over the 6-months** of the *Cost Diary*, **based on the number of times you use each service**, and a standard cost for that service that includes a portion for the direct cost to the person using the service, as well as any costs usually covered by the government or other funding bodies. As such, we need to know what type of service you used, and the length of your appointment or usage, as costs for the majority of services are based on how long the professional providing that service needs to be with you.

- 2.3.6.1.1 <u>Regular services and appointments:</u> **Service start date column**This column should reflect the **date of your first appointment or usage of the service**.
- If you were already regularly using the service at the start of the *Cost Diary*, just tick the "Active at the start of the Cost Diary" checkbox.
- See 2.3.1.1 Your regular cost tables: Start date for more information on start dates in Section A of the Cost Diary.
- 2.3.6.1.2 <u>Regular services and appointments:</u> **Type of service or appointment**This column is for the generic **name or a short description of the type of service** or allied health professional you're using. We don't need a long description or the personal name of professionals or their practise just a few key words, such as 'Acupuncture', 'Cleaning', or 'Personal assistance'.
- 2.3.6.1.3 <u>Regular services and appointments:</u> **Usual length of service or appointment**As the majority of services are charged depending on the length of the service provided, we ask you to provide the **booked (or expected) length of the service** to the nearest 15 minutes in this column.

For example, we would need to know whether you booked a 30-, 45- or 60- minute massage to provide the appropriate cost base, but we **don't** need to know if your booked 30-minute massage actually lasted 32 minutes.



2.3.6.1.4 Regular services and appointments: **Usual frequency of service or appointment**

This column is to help us calculate how many times you have used the service over the 6-months of the cost diary. There are two ways to let us know this detail, depending on how consistent your usage is:

- If your usage is very **regular and predictable**, you can use the frequency option, so you don't have to worry about remembering to record every individual use. This option is fine even if you occasionally miss appointments, or you are comfortable using an 'average' frequency that closely reflects your actual usage.
- If your usage is **less predictable**, you are welcome to use a tally system in the *Type of service or appointment* column space (or anywhere else), and then just record the total number of times you ended up using the service in the "____ total over 6-months" space at the end of the 6-months.

See 2.3.3 - Frequent, but not-quite-so-regular costs and the Your Regular Costs section for more details if you are unsure which option you should use.

2.3.6.1.5 <u>Regular services and appointments:</u> **Do you travel for this service?** Some service usage will have **travel associated with getting to where the service is offered**. If this is the case, <u>and</u> you have a fairly set routine for the use of that service, you may record the associated travel in this section.

We don't expect this travel to be a 100% accurate recording of your travel either. It is perfectly OK to say you go to the gym 3 times a week by car, but find you miss a few through illness or other appointments. Similarly, it would be fine if your car broke down and you had to take a taxi for 2 weeks until your car is fixed, or you took slightly different routes each time, depending on what else you needed to do on the day.

However, if your associated **travel** is <u>not</u> **very predictable**, either in its frequency or transport type, you may want to consider using multiple regular travel entries, or individual travel entries (see 2.2.2- Where to record your transport and how the cost is calculated).

2.3.6.1.6 Regular services and appointments: End date column

This column should reflect the date of your last appointment or last usage of the service.

If you were still using the service at the start of the *Cost Diary*, just tick the "Still active at the end of the Cost Diary" checkbox.

See 2.3.1.2 - Your regular cost tables: End date for more information on end dates in Section A of the Cost Diary.

2.3.6.2 Example: *Regular services:* Funded services, a regular health appointment, and an unpredictable frequent service with varying transport

MS has had a reasonable impact on your physical ability to juggle work and your daily home life. You have managed to secure **NDIS funding** that provides **2 hours a week** of **household cleaning** and an additional **3 hours once a month** for a **gardener**.

You've also found that getting a **massage** can really help alleviate MS related muscle stiffness. You'd love to get one every day, but have to limit your bookings due to the cost and relatively little amount of time you have to fit them in. As such, despite being something you do **fairly regularly**, there is **no real pattern** to how often you manage to get to your favourite masseuse. The random nature **also affects your transport** to the appointments. If you go directly after work you can **walk** there, but other times it is a **car trip**, or occasionally a **taxi**.

On top of the physical impacts of MS over the last few years, you've recently found that the ongoing challenges are taking their toll on your enjoyment of life in general. Your GP recommended getting help and has approved a mental health care plan that you now use to see your **psychologist for an hour once a month**. It's always easiest to have these appointments first thing before work, as the practise is only an extra **5 minutes** from your usual work parking space, and even if you have to cancel an appointment, they'll fit you in for a replacement session some time before your next scheduled monthly appointment.

MS related costs to record:

- The regular cleaning (2 hours per week) and gardening (3 hours per month) details should be recorded in Section A: Regular services and appointments.
- As they are both funded by NDIS, these entries should also be recorded in the Package Item table for NDIS funding along with the package details on page 3 (Section A: NDIS and My Aged Care package information).
- The regular **psychologist appointment** (1 hour once a month) should also be recorded in **Section A: Regular services and appointments**, along with the **travel** associated with this service (the additional **5-minute drive each way** compared to what you would be doing without the appointment).
- As the massages are frequent, but not regular, there are several options on how to record this (see 2.3.3 Frequent, but not-quite-so-regular costs and the Your Regular Costs section). The below example uses the option to make a tally mark each time you have a visit in Section A: Regular services and appointments and record the associated transport as individual entries in D3 Additional transport.
- * The completed example entries for this scenario are recorded over pages 45 47.

Other valid options for this scenario:

• The massages may be entered as individual visits with their associated travel in D1 – Appointments and other services (see 2.3.3 - Frequent, but not-quite-so-regular costs and the Your Regular Costs section).

<u>Details not to record from this scenario:</u>

Any transport for massages where you walked to the appointment.



Section A: NDIS and My Aged Care package information

	Description	Cost Diary page	Page entry number
1	Cleaning	12	# 1
2	Gardening	12	# 2

D3 – Additional transport

	Date	Travel reason	Transport type	One-way travel time	One-way distance	Cost
1	19 / 4 /2024	Massage	Car	0 0 : 1 5 h h m m	10 km	\$ 0 trip total OR
	13/4/2024	Number of legs for this trip with these one-way details: One leg only Two legs (out and back)		Part of a travel pass*		
2	25 / 4 / 2024	Massage	Taxi	0 0 : 1 5 h h m m	km	\$ 20 trip total OR
	1,72021	(p12 #4)	Number of legs for th One leg only	is trip with these one-wa	-	Part of a travel pass*
3	25 / 5 / 2024	Massage	Car	0 0 : 1 5 h h m m	10 km	\$ 0 trip total OR
	20/0/2024	(p12 #4)	Number of legs for th One leg only	is trip with these one-wa	-	Part of a travel pass*

Example 2.3.6.2 continued...

Section A: Regular services and appointments

	Service start date	Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment	
1	/ / 2024 OR Active at the start of the Cost Diary	Cleaning	0 2 : 0 0 h h m m	week times a fortnight month OR total over 6-months	
2	/ / 2024 OR Active at the start of the Cost Diary	Gardening	0 3 : 0 0 h h m m	week times a fortnight month OR total over 6-months	•
3	26 / 6 / 2024 OR Active at the start of the Cost Diary	Psychologist	0 1 : 0 0 h h m m	week times a fortnight month OR total over 6-months	
4	/ / 2024 OR Active at the start of the Cost Diary	Massage Tally:	0 0 : 4 5 h h m m	week times a fortnight month OR total over 6-months	•



Do you travel for this service?	Transport type (private car, taxi, Uber, public transport)	Travel time	Distance (private car travel only)	Transport cost	Service end date	
Yes	To service:	h h m m	km	\$ total	/ /2024	
Yes, but it's recorded elsewhere	My transport to and fro	om this service is the sa OR	ime	\$ out, and back	OR 1	
No 🗸	Return by:	h h m m	km	OR Part of a travel pass*	Still active at the end of the Cost Diary	
Yes	To service:	h h m m	km	\$ total OR	/ /2024	
Yes, but it's recorded elsewhere	My transport to and fro	om this service is the sa	ime	\$ out, and back	OR 2	<u> </u>
No 🗸	Return by:	h h m m	km	OR Part of a travel pass*	Still active at the end of the Cost Diary	
Yes 🗸	To service: Car	0 0 : 0 5 h h m m	3 km	\$ 0 total	/ /2024	
Yes, but it's recorded elsewhere	✓ My transport to and fr	om this service is the sa	ame	\$ out, and back	<u>OR</u> 3	}
No	Return by:	h h m m	km	OR Part of a travel pass*	Still active at the end of the Cost Diary	
Yes	To service:	h h m m	km	\$ total OR	/ /2024	
Yes, but it's recorded elsewhere	My transport to and fro	om this service is the sa	ime	\$ out, and back	<u>OR</u> 4	1
No	Return by:	h h m m	km	OR Part of a travel pass*	Still active at the end of the Cost Diary	

2.3.7 Your Regular Costs: Regular transport

This section is for recording any **regular trips** you may make that haven't been recorded with another entry in the "Regular memberships, subscriptions and travel passes" or "Regular services and appointments" sections.

This includes transport you have that is:

- A regular (non-service related) outing where the reason for the trip relates to your MS (e.g. once a month shopping trip to a pharmacy, or transport to a suitable (free) exercise location), or
- Further legs of transport where the initial legs are recorded with a regular service in the "Regular memberships, subscriptions and travel passes" or "Regular services and appointments" sections, or
- Any regular transport, such as for work or social outings, if MS significantly impacts how you are able to get around, or how far you can walk from your transport to your destination.

Please see 2.2 – *Transport* for more detailed information on how to record your transport and examples.

2.4 SECTION B: HOUSING AND LONG-TERM ASSETS

The *Housing and long-term assets* section is for any investments or costs you have had for your MS for items that can reasonably be expected to have a 3-year or longer lifespan. While these are generally the bigger ticket items, such as house renovations, car upgrades, furniture, or mobility items, it can also include smaller essentials, such as an electric toothbrush, or grab rails for the bathroom. You can also include upkeep and repair costs for items, as well as relocation costs for moves.

As these are generally larger, but less frequent, costs we ask that **for this section only** you include any house, car, or equipment costs from the **5 years prior to the Cost Diary**, **as well as any costs during the Cost Diary period itself**.

2.4.1 Housing and long-term assets: Private car costs

This section relates to any costs that you have incurred because of your MS that relate to the **physical structure of your private vehicle**. This may include alterations to an existing vehicle, such as the vehicle's controls or storage capacity, through to needing to purchase a more suitable vehicle altogether.

Smaller, removable purchases, such as sunshades or cushions are better suited to Section B – Pre-existing special equipment purchased or hired in the past 5 years, or C2 – New item purchases and equipment hiring (if they are purchased during the Cost Diary period).

Other **car related running costs**, such as petrol and registration, are incorporated into the transport costs in other sections and **should not be included in** *Section B*.

2.4.1.1 Private car costs – detailed information about what you need to enter

For costs you have incurred that relate to the structure of your car, we would like to know what it was that you paid for to make the car more suitable for your MS, and the full amount you (or your family) had to pay. That includes any incidental costs, such as labour, safety checks or other on-road costs required before you take possession of a car.

2.4.1.1.1 Private car costs: Car alterations tables - Alteration description

This column is for a **short description of your vehicle's alteration** and should just be a few words to let us know what was altered. For example, "modification to car controls".

You are also welcome to enter multiple alterations in one line if they were all completed by the mechanic or service provider in the same job.

2.4.1.1.2 Private car costs: *Car alterations tables - Total cost*

This column is the total cost of the alteration in dollars.

Please include any item or part costs as well as any labour costs associated with installation.

2.4.1.1.3 <u>Private car costs:</u> *Car purchases and sales* - Purchase of new car This column should reflect the **total cost** of purchasing your **new car** (in dollars), and **includes any on road costs** such as:

- All registration fees, stamp duty, or transfer fees
- Any other costs you may have incurred in purchasing the car (such as mechanical checks, interstate transport costs, installation of charging stations for electric vehicle etc.).

If you are recording an entry where you have <u>only</u> sold a car (so have no associated purchase costs), please tick the "*N/A* (*I did not buy a new car*)" checkbox, otherwise leave this checkbox blank.

2.4.1.1.4 <u>Private car costs:</u> *Car purchases and sales* - Sale of previous car This column should reflect the **final sale price** of your previous car (in dollars), **after deducting any costs you incurred** in getting the car ready for sale, such as repairs, advertising, professional cleaning or a pre-sale inspection certificate.

If you traded your old car in when purchasing a new car, you may either separately list the purchase and sale prices separately, or if you have an invoice from a car dealer that just has the final ('out of pocket') amount you had to pay, you are welcome to just tick the "Trade in price included in the purchase price" checkbox. This may be used in the case of an insurance claim on a previous car if it feels appropriate.

Finally, you may tick the "**N/A** (I did not sell a car)" checkbox to indicate you didn't have a car to sell, you have passed your old car on to a friend or family member free of charge, you have kept your old car as a backup, or you have not received any money or other type of compensation for an existing car.

2.4.1.2 Example: Common car alterations

You're finding it more and more difficult to use a standard car, but as there is no public or community transport available, you've decided the best option is to invest in adjusting the car you have to better suit your needs.

This involved installing **car hand controls**, so you no longer need to use the foot pedals. The controls themselves cost **\$4,680 to buy and install**, **and** you also opted to pay an additional **\$300** to do some specialised off-road **training** so you felt comfortable on the real road.

As your mobility is very limited now, you also paid \$8000 for installation of a 'car lift' that helps you get in and out of the car, and an additional \$5500 for installation of a wheelchair boot hoist, that means you are able to get your electric wheelchair in and out of the boot even if there is no one around to assist.

Section B: Private car costs – Car alterations

	Alteration description	Total cost
1	Car hand controls, installation and training	\$ 5000
2	Car access lifter and installation	\$ 8000
3	Wheelchair boot hoist	\$ 5500



2.4.1.3 Example: Purchasing a second-hand car (with no associated car sale)

It was time. As much as you loved your car, it was pretty low to the ground and getting harder to get in and out. You end up finding a lovely **second-hand car** that you negotiate down to **\$13,000**, but also had to **spend an extra \$2000**:

- \$200 for a prepurchase inspection
- \$400 in duty and transfer fees
- \$1400 for some minor **repairs** (tyres, wipers, minor body work)

You couldn't bear to sell your old car to a stranger though, so gave it to your son instead.

Section B: Private car costs – Car purchases and sales

	Purchase of new car	Sale of previous car
1	\$ 15,000 OR N/A (I did not buy a new car)	\$ OR The trade in price of my old car is included in the purchase price OR N/A (I did not sell a car)

2.4.1.4 Example: Selling a car (with no associated car purchase)

You don't feel overly comfortable driving around anymore, and given your partner now drives you both the majority of the time in his car, you've decided you should **sell your car**. You decide to sell privately to try and get a little more for the car, and while you get **\$12,000** as your **final sale price**, it did cost you around **\$800** to **get the car ready to sell** including:

- \$100 for a roadworthy certificate
- \$200 in advertising fees
- \$500 in pre-sale cleaning and minor fixes

Section B: Private car costs - Car purchases and sales

	Purchase of new car	Sale of previous car		
	\$	\$ 11,200		
	OR	OR OR		
1	✓ N/A (I did not buy a new car)	The trade in price of my old car is included in the purchase price		
		OR		
		N/A (I did not sell a car)		

2.4.1.5 Example: Buying a new car and trading-in your old car

You're fine to drive in general, but your left footdrop is making your manual car difficult, so you've decided to switch to a brand new automatic instead.

The cost of your new car includes a \$24,880 purchase price (including the handful of accessories you wanted), and an extra \$1,100ish of on road costs (duty and transfer fees). The dealer also gave you a trade-in price of \$6,000 for your old car, so the **final invoice total from the dealer came to \$20,021**.

Section B: Private car costs – Car purchases and sales

Purchase of new car		Sale of previous car		
1	\$ 20,000 OR N/A (I did not buy a new car)	\$ OR ✓ The trade in price of my old car is included in the purchase price OR N/A (I did not sell a car)		

2.4.2 Housing and long-term assets: Housing costs

This section relates to any costs that you have incurred because of your MS that relate to the permanent physical structure of where you live. This includes renovations, such as the installation of an air conditioner or complete bathroom renovation, through to having to move to a new house on a flatter block of land or moving to live full time in a supported nursing home.

Non-structural purchases, such as portable fans or movable ramps should be recorded in Section B – Pre-existing special equipment (purchased or hired in the past 5 years), or C2 – New item purchases and equipment hiring if they are purchased during the Cost Diary period.

2.4.2.1 Housing costs: Nursing home residency

To help us calculate the costs associated with nursing homes, we need to know if you already live full time in a nursing home, or if you move to live full time in a nursing home during the *Cost Diary* period. This includes if you are in a nursing home, and you can't 100% confidently state that MS has had absolutely NO impact on you being there, as we know it can be very difficult to separate what is an MS related symptom and what is just part of the aging process.

We will be calculating the cost of your nursing home for each day of accommodation during the 6-months of the *Cost Diary* period only, so please complete the details on **page 1** as follows:

If you didn't live full-time in a nursing home at any point during the Cost Diary period:

• For the question "At the end of your Cost Diary period, do you live full time in a nursing home at least in part due to your MS?", tick the "No, I do not live full time in a nursing home" checkbox.

If you were already living full-time in a nursing home at the start of the Cost Diary period:

- For the question "At the end of your Cost Diary period, do you live full time in a nursing home at least in part due to your MS?", tick the "Yes, I live full time in a nursing home" checkbox, AND
- For the question "When did you move to live full time in a nursing home?" tick the "I lived in a nursing home at the start of my Cost Diary period" checkbox.

If you move to live full-time in a nursing home during the Cost Diary period:

- For the question "At the end of your Cost Diary period, do you live full time in a nursing home at least in part due to your MS?", tick the "Yes, I live full time in a nursing home", AND
- For the question "When did you move to live full time in a nursing home?" enter the date you first stayed overnight in the nursing home (in the format DD/MM/YYYY)
- Finally, don't forget to complete your **moving costs**, plus any house sale costs (if applicable) in **Section B: Housing and long-term assets House costs** (see 2.4.2.5 Example: Selling up to move to a nursing home).

2.4.2.2 Housing costs – detailed information about what you need to enter

For costs that relate to the structure of your house, we would like to know what it was that you paid for to make your home more suitable for your MS, and the full amount you (or your family) had to pay. That includes any incidental costs, such as labour or approvals, or other costs associated with purchases or sales, such as conveyancing fees.

2.4.2.2.1 Housing costs: *House alterations tables* - Alteration description

The description of your house alteration does not have to be extensive, but just a few words to let us know what was altered. For example, "bathroom renovation", "hall widening" or "air conditioner installation". You are also welcome to group multiple alterations in one line if they were completed in the same job.

2.4.2.2.2 Housing costs: *House alterations tables* - Total cost

This column should reflect the **total cost of the alteration in dollars** and should also **include all material and labour costs** associated with renovation.

If you are **part way through a renovation** and have **not** paid the full amount at the end of the *Cost Diary* period, include your best estimate of the final cost, and let us know in the description that the job is incomplete and a rough guess of the expected completion date.

Similarly, if you have received part or full **funding for the renovation**, and are unsure what the total cost is, please indicate this in the *Alteration description*. Similarly, let us know if the amount you have recorded in the *Total cost* is your out-of-pocket amount (if the total cost of the renovation is not known), or the total cost for the job (regardless of what percentage was funded).

Please don't forget to **note any NDIS funded renovations in** Section A: NDIS and My Aged Care package information on page 3.

2.4.2.2.3 Housing costs: House purchases and sales tables - Purchase price of the new house

This column should reflect the **total amount** you have had to cover **in the purchase of your new home**, which **includes**:

- the **final purchase price** of the new house (in dollars), **AND**
- any other costs of settlement, such as building inspections, conveyancing, stamp duty, transfer fees, mortgage insurance, bank fees and any other incidental costs.

Please tick the "N/A (I do not own my new house)" checkbox if your entry is for a move where you do not own your new home, such as for rentals, nursing homes and temporary accommodation.

2.4.2.2.4 Housing costs: House purchases and sales tables - Sale price of the previous house

This column should reflect the **final sale price of your previous house** (in dollars), **after deducting any costs** you have incurred for the sale. These sale costs will be items such as:

- real estate fees,
- advertising,
- pre-sale home maintenance or repairs,
- conveyancing or lawyer fees,
- bank fees, including any mortgage discharge fees.

Please tick the "N/A (I was not the owner)" checkbox if your previous accommodation was not owned by you. This would be appropriate if you were renting, living with relatives, in a care facility (such as a nursing home) or you were in temporary accommodation.



2.4.2.2.5 <u>Housing costs:</u> House purchases and sales tables - Approximate relocation costs

This column should reflect the **approximate total of all the costs associated with moving**. These costs include items such as:

- removalists or other goods transport fees or truck hire,
- electricity, gas, phone, internet, or other utility reconnection fees,
- any temporary storage or accommodation fees (for misaligned moves caused by delays in settlement or availability dates of new accommodation)
- any costs associated with cleaning or repairs of previous rentals.

We do appreciate moving is an incredibly busy and stressful time, so we are happy for you to just estimate your overall cost of moving, taking into account a rough guess for any of the above listed moving costs: "I think it would have been around \$1000" is perfectly OK.

2.4.2.3 Example: Common house alterations and a partially completed renovation

The below entries in *Section B: Housing and long-term assets* (House renovations and alterations) reflect:

- Entry 1: installation of an **air conditioner** to assist with MS temperature control, where the total cost reflects:
 - The cost of the **air conditioner** itself, **and** the **installation** by the dealer, invoiced together as a total cost of \$3,500, plus
 - A further \$500 for the electrician to do the required upgrade to the switchboard to support the air conditioner.
- Entry 2: The total price of **labour and materials** (\$8,000) for the installation of **window tinting** to keep the house cool in summer and assist with MS related temperature control.
- Entry 3: This example is of a **bathroom renovation** that has a cost-plus contract that **hasn't been completed by the end of the** *Cost Diary*. As such, the final **exact cost isn't known**, but the job is currently on track to be completed at **around \$15,000**.

Section B: Housing costs – House renovations and alterations

	Alteration description	Total cost
1	Reverse cycle air conditioner installation and switchboard upgrade	\$ 4,000
2	Window tinting	\$ 8,000
3	Bathroom renovation — We are only in the initial stages of our renovation and have a cost-plus contract, so the cost recorded is our best guess. Expected completion December 2024	\$ 15,000

2.4.2.4 Example: Purchasing a new home, with the sale of your old home (with a delayed settlement)

You've had to downsize and find a new single level home on flat land, as the two stories of your previous home was getting too much for your MS symptoms. While you have been able to mostly line up the **sale and purchase**, there is a gap of a week between the settlement dates of your new and old homes that can't be avoided.

You have some lovely friends who will let you stay with them for the week, but you'll still need to pay for temporary storage of your furniture and other household goods. Your friends are also not in a 'pet friendly' rental, so your dog will have to stay at a local kennel.

The total cost for each part of your move is as follows:

Your new home costs (the 'Purchase price')	The sale of your old home (the 'Sale price')	Relocation costs
 \$300 building inspection \$320,000 for the final purchase price \$13,500-ish of settlement costs (stamp duty and transfer fees, conveyancing fees and searches, bank fees, mortgage insurance) 	 \$780,000 for the sale price \$25,000-ish of settlement costs (conveyancing fees, mortgage discharge, real estate agent advertising and commission, house preparation costs (cleaning, gardening, minor repairs)) 	 \$600-ish for dog boarding \$1000-ish for removalists and short-term storage \$300-ish in utility connection fees and mail redirection for the new house

Section B: Housing costs – House purchases and sales

	Purchase price of new house	Sale price of previous house	Approximate relocation costs
1	\$ 334,000 OR I have moved full time to a nursing home* OR N/A (I do not own my new home)	\$ 755,000 OR N/A (I was not the owner)	\$ 2,000



2.4.2.5 Example: Selling up to move to a nursing home

You've decided it's time to **sell** your unit and move full-time to a **nursing home**. It's mostly due to age, but your mild and lifelong MS symptoms don't exactly make getting older easy either.

Your unit was well looked after, so you didn't have to do anything to prepare it for sale, and the eventual agreed sale price was \$650,000. There is the usual \$22,000 of commission, fees, and charges, so after settlement you got around **\$628,000**.

As you will only have your room in the nursing home, you sold or gave away most of your furniture and other household goods, so the **moving costs** themselves were minimal, and you'd guess **probably around \$200** for some tip fees and other incidentals.

The first night you stayed overnight in the nursing home was the 5th of May.

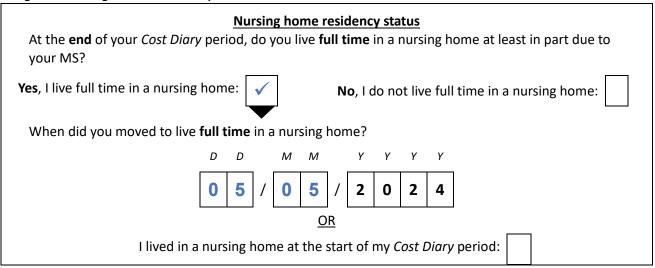
MS related costs to record:

- Record the house sale in Section B Housing costs: Purchases, sales and moves.
 Only include the house costs themselves in the sale price (house sale and settlement costs \$628,000), with the moving cost of \$200.
- For us to calculate your new **nursing home costs**, please also ensure you include the date you first stay in your nursing home overnight as a permanent resident in the *Nursing home residency status* on page 1.

Section B – Housing costs: Purchases, sales and moves

	Purchase price of new house	Sale price of previous house	Approximate relocation costs
1	\$ OR I have moved full time to a nursing home* OR N/A (I do not own my new home)	\$ 628,000 OR N/A (I was not the owner)	\$ 200

Page 1: Nursing home residency status



Details *not* to record from this scenario:

• the money received for the sale of any furniture or other household goods.

2.4.3 Housing and long-term assets: Pre-existing special equipment (purchased or hired in the past 5 years)

This section is for (non-disposable) equipment you have purchased or hired for your MS in the 5 years before your *Cost Diary* start date. This can be any household or personal item that is expected to have a 3 year or longer lifespan, whether that was a piece of furniture, a cooling vest, or some non-slip stickers for the bath.

Please note: We still need details of purchases of non-disposable equipment during the *Cost Diary* period, but these should be recorded in *C2 - New item purchases and equipment hiring*.

2.4.3.1 Pre-existing special equipment (purchased or hired in the past 5 years) – detailed information about what you need to enter

In order for us to calculate your longer-term asset costs and correctly categorise them, we just need a short description of the item, and how much you personally paid for it.

2.4.3.1.1 Pre-existing special equipment: Item description

In this column, please provide us with a description of the item so that we can accurately identify the purchase. While we always need the **name of the item**, other details that are helpful (if applicable) **include**:

- **The number of items** included in the price (if you bought more than one of the same item)
- The expected **location** for household items (e.g. <u>kitchen</u> chairs, <u>bathroom</u> trolley)
- For **hired items**, please indicate the **approximate length of time** the amount you paid has covered (this may include time during the *Cost Diary* period itself if you had already started hiring an item when the *Cost Diary* began).

2.4.3.1.2 Pre-existing special equipment: Amount paid by you

This column should reflect the amount **you** (or your direct family or friend) **paid** for the item, **including any setup or delivery fees**. Noting:

- 1. We are happy for the amount to be rounded to the nearest dollar (or \$10, or \$100 for larger purchases if you can't remember or don't know).
- 2. If items were funded, or you were reimbursed some of the cost, record the total 'out of pocket' you paid, and just put a tag of "*funding received" so we know this wasn't the full cost of the item. This includes fully funded items, where you didn't have to pay anything personally. If this was NDIS or My Aged Care funding, please remember to tag the item in Section A: NDIS and My Aged Care package information.
- 3. For **hired items**, put the total amount you paid for the hire period <u>OR</u> the amount of each instalment with an associated note of how many instalments you have paid at this rate.

2.4.3.1.3 Pre-existing special equipment: **Tick if this item was hired**

Please tick the corresponding checkbox if the item you have recorded is hired. Leave it blank for items you purchase to own, even if there is an associated loan or layby.



2.4.3.2 Example: Common pre-existing special equipment (purchased or hired in the past 5 years)

The following records are all suitable items that have been purchased or hired during the 5 years leading up to the *Cost Diary* start date. Of particular note:

- Entry 1: Is for 2 years' worth of wheelchair hire, that started a year ago, and will continue through the full 6 months of the Cost Diary. The hire is subsidised through funding the MS Society helped you get, and you only personally pay \$100 a year (and have no idea how much it costs the funding body).
- Entry 6: Is for a magnifier you really needed for your craft, as MS is affecting your close work eyesight. It was given to you by a friend though, and you don't know how much it cost.
- Entry 9: Is for special voice recognition computer software you can use when your hands are too sore.
- Entry 10: Is for the shower chair you received that was fully funded, so didn't have to pay anything for it.
- Entry 15: Is the TENS machine you originally hired for only a month to help with nerve pain, but it was so good that you kept paying the \$25 a month for 6 months.

Section B: Pre-existing special equipment

	Item description	Amount you paid	Tick if this item was hired
1	Wheelchair hire (2 years) - subsidised	\$ 200	✓
2	Walking stick	\$ 30	
3	Orthotics	\$ 120	
4	Wheelchair cushion	\$ 100	
5	Hand weights	\$ 20	
6	Magnifier	\$ 0	
7	Sunglasses	\$ 300	
8	Ice vest	\$ 250	
9	Computer software	\$ 1800	
10	Shower chair (fully funded)	\$ 0	
11	Electric toothbrush	\$ 120	
12	Non-slip shower spots	\$ 25	
13	Jar opener	\$ 35	
14	Portable fan	\$ 200	
15	TENS machine (\$25 a month x 6 months)	\$ 6 x \$25	✓

2.5 SECTION C: PURCHASES

The blue purchases section is for the day-to-day purchase (or hire) of any physical items related to your MS during the 6-months of the *Cost Diary* period.

2.5.1 Using barcodes to identify purchases

The quickest and most accurate way to record any purchases is by writing down the 11-13 digit barcode number located just below the striped lines of the barcode itself on the packaging of many purchases:



As barcodes are unique even for different sizes of the same product, recording the barcode number lets us identify the exact product you have purchased, and provides the detailed information we require without you having to record further details (aside from a short name so we can double check the barcode matches your expected purchase).

We request you record the barcode of your purchases wherever possible.

However, we do know there are cases where the barcode number won't be available, such as for second hand, hired, or larger items. In these cases, please provide detailed information so we can correctly identify the purchase, including brand, name of the item, and quantities.

2.5.2 Purchases: Medications and supplements

This section is for **all** your medications and supplements, both prescription and over the counter, regardless of whether they are directly associated with your MS or not.

This includes:

- All prescription AND non-prescription (over the counter) medication,
- All vitamin or mineral supplements,
- All tablets, capsules, liquids, gels, patches, creams, ointments, inhalers, sprays, powders, lozenges and drops.

Unlike many other purchases, medications and supplements are charged at a reasonably standard cost. There is always going to be some variance due to purchase location, and you may be lucky enough to buy some items on special, but as a whole, we already know the price of these items, so only need you to tell us what you bought, not how much it cost.

2.5.2.1 Medications and supplements – detailed information about what you need to enter

We will be calculating the cost for all medications and supplements you buy over the 6-months of the *Cost Diary*. We don't require the exact price for each purchase, just the details to correctly identify the brand and size of what you bought.

2.5.2.1.1 Medications and supplements: Brand and medication name

This column is for the **brand** that makes the medication or supplement **and the name** of the medication or supplement itself. Examples would be Panadol Osteo, Cenovis B Complex, or Symbicort Turbuhaler.

If you are recording a **barcode** to identify your purchase, you may **abbreviate or shorten the name**, as we will just be using it as a double check that the recorded barcode matches what is expected.

If you are **unable to record the barcode**, please ensure you record **the full name and brand**, and any other listed information on the packaging that will help us identify the correct type of product you purchased.

2.5.2.1.2 <u>Medications and supplements:</u> **Medication identifying details**

This column is for the key details that will let us identify your exact purchase.

We request that you **record the barcode number wherever possible in this column** (see 2.5.1 - Using barcodes to identify purchases), as this will provide the exact details we need.

If you can't find, or no longer have the barcode, please provide us with as much detail as possible so we can make sure we have the right product. At a minimum, this needs to be:

- The active ingredient strength: This is often listed on the packaging under the name of the product but can also be found elsewhere with a heading of "Active ingredients", "Each does contains..." or similar. It is generally in mg (or μg) for solids, and "mg per mL" (mg/mL) for liquids but does depend on the medication. Some medications and supplements will have multiple active ingredients. For those with two or more active ingredients, record at least the first two, and if you can fit one or two more, please do so as it will help us confirm we have the right product. See 2.5.2.2 Example: Active ingredients of medications and supplements.
- The size of the packet or bottle you bought: This is how many 'doses' of the medication there are in the packet, i.e. the number of tablets, capsules, injections, or patches, or the volume (or weight) of creams, gels, and liquids. For examples see 2.5.2.3 Example: Packet or bottle size of medications and supplements.





2.5.2.1.3 <u>Medications and supplements:</u> Tick for prescription medication
Please tick the checkbox in this column if you used a prescription from a doctor or other
health practitioner to purchase this medication. Leave it blank if you didn't use a
prescription (i.e. it was an 'over the counter' medication or a supplement).

2.5.2.1.4 <u>Medications and supplements:</u> **Number of packets or bottles bought**This column is to reflect **how many packets or bottles of the medication or supplement you purchased**, either in an individual purchase, or as a total over the 6-months.

We know many people will have **regular medication** that they either buy in bulk or will frequently purchase throughout the 6-month period. If this is the case, you don't need to keep re-entering the details of your regular medication, as you are welcome to use one entry, and **use the "tally space"** to keep track of the total number of packets or bottles each time you make a purchase. **At the end of the 6-month period**, just record the **total number** of packets or bottles purchased in the "**Total over the 6 months**" column.

If you prefer, however, you are of course welcome to use a different entry with full details each time you make a purchase. In this case, just use the "Total over the 6 months" column to record how many packets you purchased in that one transaction.

If you do choose to use one entry for regular medication, the following is a guide to what is OK to record in the same entry and what you should record as separate entries:

OK to record in the same entry	Record as separate entries	
 The exact same item but purchased at a different price. If your usual medication isn't available: Purchases of multiple smaller packets to make up to the same size as your usual purchase (e.g. 2 x 50 tablet packets if the 100 tablet packet isn't available is OK to record as 1 purchase of your 'usual' 100 tablet packet) Brand substitution of the same size and active ingredient 	 The same product, but different sized packets (unless your preferred choice is unavailable) Different brands of the same size and active ingredient (unless your preferred choice is unavailable) 	

2.5.2.2 Example: Active ingredients of medications and supplements

Below are some examples of medications and supplements and where to find their **active ingredients** on the packaging.



2x3PATCHES

ONCE DAILY

NASONEX DNEX





2.5.2.3 Example: Packet or bottle size of medications and supplements

Below are examples of medications and supplements and their packet or bottle size as listed on the packaging.

Medication or supplement packaging	Packet or bottle size	Medication or supplement packaging	Packet or bottle size
PHARMACY MEDICINE PHARMACY MEDICINE Tablets Paracetamol 500 mg ""extive on pain " Gestile on stomacks"	100 tablets	Savion ANTISEPTIC CREAM AUT 1/207 50g NET Craides Circles developation to large, Common Engly, Promorphism 1, Engly, Promorphism 2, Engly, For any base and panel.	50 g
Strepsils EXTRA Hexylresorcinol 2.4 mg Anaesthetic + Antibacterial Rapid relief from painful sore throats Numbs sore throats Helps fight bacteria 36 LOZENGES Blackcurrant Flavour	36 lozenges	WALUE PACK 4 PATCHES BACK PAIN EXTRA-LARGE HEAT PATCHES BY SAIN RELIEF HEAT THERAPY SIGNATURE POWER SUBMIT SPAIN RELIEF Plant THERAPY SIGNATURE OF THE STATE OF THE STATE POWER SAIN PROVIDE SOCIAL PROPERTY OF THE STATE SIGNATURE OF THE STATE A POWER SAIN PROVIDE SIGNATURE OF THE STATE A POWER SAIN PROVIDE SIGNATURE OF THE STATE A POWER SAIN PROVIDE A STATE OF THE STATE A POWER SAIN PROVIDE A POWER SAIN	4pk of XL
PHARMACY MEDICINE EFFORT O HARM OCHER LEVOCABASTINE NASAL SPRAY RELIEVES MAYFEYER A ALLERY SYMPTOMS PORMAN PORMAN FROM DROWS PORMAN EMMY MORE TOML 100 9885	10 mL OR 100 sprays OR 10 mL / 100 sprays	PHARMACY MEDICINE ISPOSION BAZANT GUINNA CETTINZINE SUGAR FREE ORAL DROPS 12 RELIEVES HAYFEVER BALLERY SYMPTOMS ALLERY SYMPTOMS MATERY TICHY SKIN RASH 14 14 15 16 17 18 18 18 18 18 18 18 18 18	20 mL
Lubricating eye drops Suttable for one with contact cores. Sedim playmante 1 mg/m. Welking playchate-line eye for the male 1 mg/m. Welking playchate-line eye for the male 1 mg/m. Welking playchate-line eye for the mg/m.	10 mL	VICKS INHALER FAMILY PACK VICKS Inhaler Menthol 197mg Garaphor 197my Subas Breething foul Gara and Con St 0.5 sat Ant uses Ant uses	3 x 0.5 mL

SECTION C: PURCHASES - MEDICATIONS AND SUPPLEMENTS

2.5.2.4 Example: Medications and supplements, barcodes and multiple purchases

The following examples for recording medications and supplements include **prescription medication** (1 and 5), **over-the-counter** medications and supplements (2, 3 and 4), **barcodes** from the packaging (1, 2, 3 and 5), extra details for when there is **no barcode** (4), recording **multiple purchases of the same product** (1, 2 and 3), **one-off purchases** (4 and 5).

C1 – Medications and supplements

Brand and medication			Tick for	Number of packets purchased	
	name	Medication identifying details	prescription medication	Tally space	Total over the 6 months
1	Gilenya	Barcode: 3 0 0 7 8 0 6 0 7 1 5 5 OR Active ingredient strength: Packet size/bottle volume:	>	 	7
2	Herbs of Gold Vitamin D3	Barcode: 9 3 1 3 9 2 3 1 2 0 1 1 5 OR Active ingredient strength: Packet size/bottle volume:		II	2
3	Panadol Rapid	Barcode: 9 3 0 0 6 7 3 8 4 0 9 8 1 OR Active ingredient strength: Packet size/bottle volume:		2 3	3
4	Swisse (Ultiboost) Magnesium (Bone and Muscle health)	Active ingredient strength: Magnesium (from citrate) 150mg Packet size/bottle volume: 300 film coated tablets			1
5	Endep	Barcode: 3 1 6 7 2 9 1 7 2 1 7 2 OR Active ingredient strength: Packet size/bottle volume:	✓	I	1

2.5.3 Purchases: New item purchases and equipment hiring

This section is for **physical items you purchase**, **hire or receive** for your MS over the 6-months of the *Cost Diary*. This can be anything from an easy grip pen, through to an electric wheelchair. There are only 3 categories of purchases that **need to be recorded** elsewhere:

- 1. All your **medications and supplements** should be recorded in **C1 Medications and Supplements** (see 2.5.2 Purchases: Medications and supplements).
- 2. Costs related to the **structure of your house**, including purchasing a house itself, should be recorded in **Section B Housing and long-term assets** (see 2.4.2 Housing and long-term assets: Housing costs).
- 3. Costs related to the **structure of your car**, including purchasing a car itself, should be recorded in **Section B Housing and long-term assets** (see 2.4.1 Housing and long-term assets: Private car costs).

Please also remember that any equipment or non-disposable items you have purchased for your MS over the 5 years prior to the *Cost Diary* period can be recorded in *Section B:* Housing and long-term assets.

2.5.3.1 New item purchases and equipment hiring – detailed information about what you need to enter

To calculate the cost of MS related purchases over the 6-months of the *Cost Diary*, we only require a **brief description** of the item, the **barcode** (if available) and the **amount you personally paid for the item**.

2.5.3.1.1 New item purchases and equipment hiring: Date

The **date** column is **not mandatory** and can be specific (DD/MM/YYYY) or more general (e.g. month only). This column is more a prompt for you to double check your entries at the end of the 6-months, especially for any regular/repeat purchases you may make, so an exact, accurate date is NOT required for purchases.

2.5.3.1.2 New item purchases and equipment hiring: Item description

The easiest way for us to definitively identify your purchase is for you to **provide the barcode number if it exists** (see 2.5.1 - Using barcodes to identify purchases), **along with** a very **short 2-3 word description** for barcode verification.

If you **don't have a barcode**, please provide us with **as much detail as possible** in the description so we can accurately identify the purchase. While we always need the name of the item, other details that are helpful (if applicable) **include**:

- The **brand** of the item
- The **number of items** purchased (if more than one)
- The **location** for household items (e.g. **kitchen** chairs, **bathroom** trolley)
- For **hired items**, please indicate the **approximate length of time** covered by the recorded payment amount (this may include time before or after the *Cost Diary* period itself if the hire period includes time outside the 6-months).

2.5.3.1.3 New item purchases and equipment hiring: Amount paid by you This column should reflect the amount you (or your direct family or friend) paid for the item, including any setup or delivery fees. Noting:

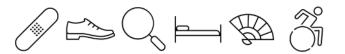
- 1. We are happy for the amount to be rounded to the nearest dollar (or \$10, or \$100 for larger purchases if you can't remember or don't know).
- 2. If items were **funded**, **or** you were **reimbursed** some of the cost, **record the total 'out of pocket' you paid**, and just put a tag of "*funding received" so we know this wasn't the full cost of the item. **This includes fully funded items**, where you didn't have to pay anything personally.
- 3. For hired items, put the total amount you paid for the hire period <u>OR</u> the amount of each instalment with an associated note of how many instalments you have paid at this rate.
- 2.5.3.1.4 New item purchases and equipment hiring: **Tick if this item was hired**Please tick the corresponding checkbox if the item you have recorded is hired. Leave it blank for items you purchase to own, even if there is an associated loan or layby.

2.5.3.2 Example: Common item purchases and equipment hiring

The following examples include barcoded items (2 and 3), details for non-barcoded items (1 and 4), location details for household items (1 and 4), a multiple item purchase (2), a purchase without a recorded date (4).

C2 – New item purchases and equipment hiring

	Date	Item description	Amount you paid	Tick for hired items
1	1/4/2024	(one) ergonomic office chair Barcode:	\$ 300	
2	4/4/2024	Hygiene Plus disposable gloves (3 packs of 100 - \$12 each) Barcode: 9 3 2 2 5 9 6 0 0 1 7 7 5	\$ 36	
3	20 / 5 / 2024	Napisan Barcode: 9 3 0 0 7 0 1 0 8 4 7 7 6	\$ 15	
4	/ /2024	Hand-held shower hose Barcode:	\$ 80	



2.5.3.3 Example: Multiple purchases of the same item (with pricing inconsistencies)

You **regularly purchase continence pants** when you do your weekly supermarket shop. You do try to buy a **few extra packets when they're on special (\$12-\$14)**, but **often pay** the **full price** of **\$18** as you can't really go without them. You've also been caught out **once or twice**, and had to buy them at the local pharmacy, where your **preferred brand is more expensive (\$22)**. You also had to buy a **different brand once** from the supermarket, as your **favourite brand was out of stock**.

MS related costs to record:

Even though there was **some variety** in the **price and brand** for your purchases over the 6-months, the **intention was to get the same brand** and it generally cost you \$18 (a couple more expensive, a couple cheaper). Therefore, you are welcome to just **use the same entry**, and **use the regular price of \$18** to calculate your total paid.

C2 – New item purchases and equipment hiring

Date Item description			Amount you paid	Tick for hired items
1	/ /2024	Depends (continence pants) - \$18 each Tally:	(Total: 8 x \$18) \$ 144	

Note: You are also welcome to record each purchase as a separate entry if you choose.

2.5.3.4 Example: Continuous hiring of an item before or after the Cost Diary dates

A few weeks **before** your **Cost Diary start date** you had a **fall**, that you would say was caused by vision problems associated with MS. The fall resulted in a badly sprained ankle, and instead of crutches you decided to **hire a knee scooter** as it gave you better ability to stand and have your hands free

Your local mobility business charged \$150 for 6 week's hire, and that included dropping the scooter in to you and then picking it back up at the end of the hire period.

MS related costs to record: Even though the initial incident was before your *Cost Diary* start date, remember that we are including equipment costs from the last 5 years prior to the *Cost Diary*, as well as during the 6-months of the *Cost Diary* itself.

The below example is **recorded in** *C2 – New item purchases and equipment hiring*, but it would be **equally valid** to be **in** *Section B – Pre-existing special equipment*. However, note that it **should only be recorded in one section**, not both.

Please remember to record a description or the hired item and the hire period the cost relates to in your Item description.

C2 – New item purchases and equipment hiring

Date Item description		Amount you paid	Tick for hired items	
1	1/3/2024	Knee walker (6-week hire) Barcode:	\$ 150	✓

If you had the same scenario, but the 6-week hire period was going to end AFTER the *Cost Diary* end date, please still just include the total amount you paid (\$150) for the full 6-weeks in *C2 – New item purchases and equipment hiring*. That is, the entry would look the same as the above example, just with a later 'date'.

SECTION C: PURCHASES - NEW ITEM PURCHASES AND EQUIPMENT HIRING

2.5.3.5 <u>Example:</u> Entries where you receive funding (or a rebate) to help pay for an item

Every second month or so you order a carton of **disposable bed pads** that is **fully funded** by your **NDIS package**.

You've also required **new glasses** recently, which cost \$860 total. Luckily **\$400** was **covered by your private health**, so you were **\$460 out of pocket** in the end.

MS related costs to record:

For these purchases:

- For the disposable bed pads, record the entry in *C2 New item purchases and equipment hiring* with \$0 for the *Amount you paid*, and a note saying this is funded by NDIS. Also remember to record this entry number in the table of NDIS supplied services on page 3 (*Section A: NDIS and My Aged Care package information*).
- For the glasses, record the entry in *C2 New item purchases and equipment hiring* with \$480 for the *Amount you paid*, and a note saying some was paid by your private health. If you know the amount paid by private health, you are welcome to include the amount in the description, but this is not vital.

C2 – New item purchases and equipment hiring

	Date	Item description	Amount you paid	Tick for hired items
1	12 / 4 / 2024	Glasses (prescription) *private health paid some Barcode:	\$ 480	
2	4/5/2024	Abrena – Abri-soft Superdry disposable soft underpads (bed protectors) – 60 pcs * NDIS funded Tally: III Barcode: 9 3 2 2 5 9 6 0 0 1 4 3 2	Total: 3 x 60 pack \$ 0	

Section A: NDIS and My Aged Care package information

Description		Cost Diary page	Page entry number
1	Bed protectors	42	# 2

2.6 SECTION D: SERVICE USAGE AND TRANSPORT

Any day-to-day services and additional one-off transport you use during the 6-months of the *Cost Diary* period should be recorded in the green *Section D: Service usage and transport*.

2.6.1 Service usage and transport: Appointments and other services

The Appointments and other services section is likely to be one of your most used sections over the 6-month period of the Cost Diary as it includes the majority of costs linked to your MS when someone helps you, or you have used an available service. This **includes**:

- All medical, allied and general health professionals (e.g. doctors, specialists, nurses, physiotherapists, occupational therapists, pharmacists, psychologists, hospital day procedures)
- All general health services (e.g. exercise and movement classes, gym or pool visits, massages, hydrotherapy)
- All assistance services (cleaners, personal carers, gardeners, tradesmen)
- All support services (e.g. MS societies, social workers, NDIS case managers, employment services, bank managers)

This section is for **single entries** of your **one-off** or **infrequent** day to day **services**.

Please note, services that should be recorded elsewhere include:

- 1. **Services you use frequently**: If you are a frequent user of a service (once or more a month), consider using *Section A: Regular services and appointments* to cut down the numbers of entries you need to make. See *2.3.6 Your Regular Costs: Regular services and appointments* for more details.
- 2. **Overnight stays and extended care**: Any time you are cared for overnight (or longer) in a health care setting, it should be entered in the *D4 Temporary hospital and health care admissions* section. This includes 'hospital in the home' care. See *2.6.4 Service usage and transport: Temporary hospital and health care admissions* for more details.
- 3. **Medical tests and scans**: Medical tests and scans should be recorded in *D2 Medical Tests and Scans*, where the calculated costs will include the professionals associated in performing that test and preparing the test results. See *2.6.2 Service usage and transport: Medical tests and scans* for more details.
 - Please note: We do still need you to record the appointment or visit where you received the referral for tests or scans in section D1 Appointments and service usage, as well as any follow-up appointments with your doctor or specialist that may occur from the test results.

2.6.1.1 Appointments and other services – detailed information about what you need to enter

To calculate the cost of each of your services, we need the following details:

2.6.1.1.1 Appointments and other services: **Date**

The date column is **not mandatory** and can be specific (DD/MM/YYYY) or general (month only). This column is only a prompt for you to double check your entries at the end of the 6-months, especially for any regular or repeat services you may use, so an exact, accurate date is NOT required.

2.6.1.1.2 Appointments and other services: Service type

This column is for a **short description** of the **service you used or received** and can just reflect what term you would most likely use to do a look up providers close to you in the phone book or using Google. For example, if you needed someone to do shopping for you, you may look up 'personal assistance' and then add 'shopping' to refine your search.

We <u>do not</u> need you to let us know the personal name or practise of the provider you used, just the type of service they provided.

2.6.1.1.3 Appointments and other services: Length of appointment

As the majority of services are charged depending on the length of time of the provided service, we ask you to provide the **booked (or expected) length of the service** to the **nearest 15 minutes** in this column.

For example, we would need to know whether you booked a 30-, 45- or 60- minute massage to provide the appropriate cost base, but we *don't* need to know if your booked 30-minute massage actually lasted 32 minutes.

2.6.1.1.4 Appointments and other services: Type of appointment

To correctly allocate costs, we need to know if your **professional services or appointments** were conducted:

- Face-to-face: with you and the professional in the same room, or
- **Telehealth**: with you and the professional **in separate locations** (e.g. by phone or online platform such as Zoom).

While this column will not apply to some services you use (for example, it doesn't make sense to attend a sauna via Telehealth), we request you **tick the "face-to-face" checkbox for**<u>ANY</u> **non-Telehealth appointments**, just to make sure you don't get out of the habit of looking at this column for the services that we DO require this information.

2.6.1.1.5 Appointments and other services: Did you travel for this service? Some service usage will have travel associated with getting to where the service is offered. If this is the case, and you haven't recorded the transport elsewhere, you may choose to record your associated travel in this section. See 2.2.2 - Where to record your transport and how the cost is calculated for more details.







2.6.1.2 Example: One-off service usage

The following examples include a medical professional appointment (1), an assistance service (2), a support service (3 and 4), a day hospital procedure (5), and an allied health appointment (6).

Other important notes are the two **Telehealth appointments** conducted over the phone (1 and 4), and the **valid partially completed date** (2).

D1 – Appointments and other services

	Date	Service type	Length of appointment	Type of appointment	
1	10 / 4 / 2024	GP	0 0 : 1 5 h h m m	Face-to-face Telehealth	
2	/ 4 / 2024	Handyman (fix a cupboard)	0 0 : 3 0 h h m m	Face-to-face Telehealth	
3	1/5/2024	MS Society appointment (employment assistance)	0 1 : 0 0 h h m m	Face-to-face Telehealth	
4	8/5/2024	MS Society follow-up	0 0 : 1 5 h h m m	Face-to-face Telehealth	
5	21 / 5 / 2024	Ocrevus infusion (private hospital)	0 4 : 0 0 h h m m	Face-to-face Telehealth	
6	7/6/2024	Massage	0 0 : 4 5 h h m m	Face-to-face Telehealth	

2.6.1.3 Example: Multiple services for one incident: Emergency room attendance with tests and follow-up care

An **MS related fall** results in a **sore wrist** that needs to get checked out immediately at the closest **hospital emergency department**. An **x-ray** at the hospital reveals there is a break, and a **cast** is put on **before you are allowed home** with a radiology referral for an **x-ray in 6-weeks' time** to ensure the break has healed.

After the 6-weeks, you make the appointment at your local radiology practise, and your **doctor's surgery** calls the next day to let you know all is good, and **makes an appointment** for you to come in, get the **cast removed and have a follow-up check** to ensure everything under the cast is OK.

The doctor gives the all clear, but your wrist is very weak, so requires **fortnightly physiotherapy appointments** and home exercise **for 3 months** to regain strength and movement.

<u>Note:</u> At times, you may need to include several different appointment and service entries for one medical incident. This especially relates to emergency department attendance, or doctors' surgeries that have in-house pathology capability. In short, if your invoice from your provider has (or would have) multiple line items, consider recording them each separately.

MS related costs to record:

- Record the visit details to the emergency department in D4 Temporary hospital and health care admissions, which will include the medical service cost of the emergency physician and cost of the cast.
- 2. Record the **initial x-ray** of your wrist at the hospital in **D2 Medical tests and scans** (there is no need to record the radiographer separately, as they are included in the x-ray cost).
- 3. Record the **follow-up x-ray** of your wrist after 6-weeks' recovery in **D2 Medical tests and scans**.
- 4. Record the **follow-up visit** to the **doctor** for the cast removal and assessment in **D1 Appointments and other services**.
- 5. Record the **fortnightly physiotherapy** appointments for the **three months** in **Section A Regular services and appointments**.







D4 - Temporary hospital and health care admissions

Α	Accommodation type Reason for admission		Dates		
			Admission date:	2 / 4 / 2024	
			OF	१	1
1	Emergency department	Fall resulting in broken wrist	I was here at the Cost Di	start of the iary period:	
	(Public hospital)	(X-ray and cast)	Discharge date:	2 / 4 / 2024	
			OF	R	
			I have not been (at end of Cost D	-	

D2 - Medical tests and scans

	D2 - Iviedicui tests diid scans					
Date		Date	Test or scan type	Do you travel for this test?		
	1	2/4/2024	X-ray (at hospital for wrist)	Yes, but it's recorded elsewhere		
	2	15 / 5 / 2024	X-ray (Follow-up for wrist)	Yes, but it's recorded elsewhere		

D1 - Appointments and services

Date	Service type	Length of appointment	Type of appointment	
17 / 5 / 2024	GP (broken wrist follow-up)	0 0 : 1 5 h h m m	Face-to-face Telehealth	

Section A – Regular services and appointments

Service start date		Type of service or appointment	Usual length of service or appointment	Usual frequency of service or appointment	
1	21 / 5 / 2024 OR Active at the start of the Cost Diary	Physio (broken wrist rehab)	0 0 : 3 0 h h m m	week times a fortnight month OR total over 6-months	

2.6.2 Service usage and transport: Medical tests and scans

This section is for all the **tests and scans that require a referral authorised by a medical professional**, whether they are performed in a medical practice, hospital, or at a separate testing facility.

Medical tests and scans include:

- All pathology tests (e.g. blood, urine and stool tests)
- All scans (e.g. MRI, CT)
- All tests by a specialist diagnostician or specialised equipment (e.g. ECG, ultrasounds, thyroid tests, nerve conduction studies)

There is **no need to include basic health examinations** that occur in general health appointments, such as:

- Stethoscope (pulse rate) or otoscope (ear or throat) examinations
- Blood pressure
- Examinations performed by the physician themselves, such as range of motion or pain location tests.
- Basic vision tests (eye charts and distance/focus testing) **do** include other machine or specialist based optical tests.

2.6.2.1 Medical tests and scans – detailed information about what you need to enter The details required to calculate the cost of medical tests and scans only includes a **description or name** of the test or scan.

2.6.2.1.1 Medical tests and scans: **Date**

The date column is **not mandatory** and can be specific (DD/MM/YYYY) or general (month only). This column is a prompt for you to double check your entries at the end of the 6-months, so an exact, accurate date is NOT required.

2.6.2.1.2 Medical tests and scans: **Test or scan type**

This column is for the **short medical description** of the test or scan you have had, **and** the **part of the body** that was tested or scanned (if applicable).

If you have the referral for your test or scan, the "Tests requested", "Examination requested" or "Referral information" sections should have the type of test (abbreviations as they appear on the referral are fine).

If your **referral includes multiple tests** (as often occurs with blood tests), it is also OK to record them all in the one entry.

If you are **unsure of the exact tests** you have had, especially with regards to hospital or emergency admissions, just give us as much information as you remember.

2.6.2.1.3 Medical tests and scans: Did you travel for this service?

Many tests will have **travel associated with getting to the testing facility**. If this is the case, and you haven't recorded the transport elsewhere, you may choose to record your associated travel in this section. See 2.2.2 - Where to record your transport and how the cost is calculated for more details.





2.6.2.2 Example: Common medical tests and scans

The following examples include a scan (1), and multiple tests done in one visit (2). Also note the related body part entered for relevant tests (1 and 4).

D2 - Medical tests and scans

	Date	Test or scan type	Do you travel for this test?	
1	2/4/2024	MRI (brain)	Yes, but it's recorded elsewhere	
2	21 / 4 / 2024	Blood tests (Full blood count and JCV)	Yes, but it's recorded elsewhere	
3	28 / 4 / 2024	Liver function test	Yes, but it's recorded elsewhere No	
4	1/5/2024	X-Ray (knee)	Yes, but it's recorded elsewhere	

2.6.3 Service usage and transport: Additional transport

This section is for recording any **one-off trips or extra legs** of journeys that haven't been recorded elsewhere. This includes transport you have that is **either**:

- A trip where the type of transport you use or the distance from your transport to your ultimate destination needs to be planned with consideration of your MS symptoms (e.g. for work, shopping, or social outings), OR
- An outing where the **reason for the trip relates to your MS** (e.g. a trip to buy medication or gloves), OR
- Another leg for transport that is recorded elsewhere in Section D: Service usage and transport section.

Please see 2.2 - Transport for more detailed information on how to record your transport and examples.

2.6.4 Service usage and transport: Temporary hospital and health care admissions

This section is for your hospital **accident and emergency attendance**, **overnight (or longer) stays** in medical facilities or **extended after procedure care** associated with 'hospital in the home' related to your MS including:

- All hospital admissions (e.g. operations, accident and emergency attendance, other overnight and longer admissions)
- Rehabilitation admissions
- Hospital in the home
- Respite care

Please note, items to record elsewhere include:

- **Planned day procedures**, including DMT infusions, should be entered in *Appointments and other services* (see 2.6.1 Service usage and transport: *Appointments and other* services).
- **Permanent moves to nursing home facilities** should be recorded in *Nursing home residency status* (see 2.4.2.1 Housing costs: Nursing home residency).

2.6.4.1 Temporary hospital and health care admissions – detailed information about what you need to enter

To calculate the cost of your temporary admissions, we need to know what **type of accommodation** you stayed in, **why** you were there, and for **how long** you had to stay.

- 2.6.4.1.1 <u>Temporary hospital and health care admissions:</u> **Accommodation type**This is the **general type of facility** where you were provided care, noting you <u>do not</u> have to supply the name of the facility itself. The most common entries for this column will be:
 - Public hospital
 - Private hospital
 - Respite facility (including nursing homes)
 - Rehabilitation facility
 - Hospital-in-the-home
- 2.6.4.1.2 <u>Temporary hospital and health care admissions</u>: **Reason for admission**This column is for **a very brief summary of your reason for care** to ensure we correctly estimate associated costs. Common examples are:
 - A planned procedure or operation (please give a very brief description, e.g. "knee surgery")
 - An unplanned procedure or accident
 - Illness
 - Respite
 - Rehabilitation
- 2.6.4.1.3 <u>Temporary hospital and health care admissions:</u> **Dates**We will be calculating the **daily cost** of your care **during the** *Cost Diary* **period itself**. As such:
 - the admission and discharge dates recorded do <u>not</u> have to be 100% accurate, as long as the dates represent the length of your stay (as best as you are able to recall). For example, you can't remember the exact dates, but you can record a start date of 1/5/2024 and an end date 17/5/2024 to reflect a 2 week and 2 day stay in hospital.
 - If you were staying (temporarily) in a health care facility at the <u>start</u> of your *Cost*Diary period, you do not need to remember your admission date, but just tick the "I was here at the start of the Cost Diary period" checkbox.
 - Similarly, if you were still (temporarily) staying in a health care facility at the end of the 6-month Cost Diary period, you do not need to guess a discharge date, but just tick the "I have not been discharged (at the end of the Cost Diary period)" checkbox.
- 2.6.4.1.4 <u>Temporary hospital and health care admissions:</u> **Did you travel for this service?**

Travel will generally be required **to get to health care admissions**, and you should enter this travel with your admission details in this section. The only exception will be hospital-in-the-home details, where you may leave the transport section blank.

See 2.2.2 - Where to record your transport and how the cost is calculated for more details.





2.6.4.2 Example: Temporary hospital admission for a planned procedure followed by hospital-in-the-home care

You had a fall late last year that you link to your MS foot drop. The fall resulted in knee damage, that required non-urgent surgery. You finally got the surgery in May, which required a brief overnight stay. As you had no one available to assist you at home after the surgery, you received approved hospital-in-the-home care until a week and a bit later you were assessed as having recovered enough to resume looking after yourself.

D4 – Temporary hospital and health care admissions

	Accommodation type	Reason for admission	Dates	
			Admission date: 2 / 5 / 2024	
1	Private hospital	Knee surgery	OR I was here at the start of the Cost Diary period: Discharge date: 4/5/2024 OR	•
			I have not been discharged: (at end of Cost Diary period)	
	At home	Hospital-in-the-home (post knee operation care)	Admission date: 4 / 5 / 2024	
2			Discharge date: 15 / 5 / 2024	
			OR I have not been discharged: (at end of Cost Diary period)	

2.7 SECTION E: NOTES AND COMMENTS

There are 'Notes and comments' sections at the end of each individual cost section, as well as an overall, independent Section E: Notes and comments section at the end of the Cost Diary.

You may use these sections however you wish, including:

- Extra information you feel is relevant to your costs (please also note the page and item numbers if your information relates directly to a recorded cost).
- Comments, questions or feedback you may like to pass on.
- Summaries or tallies about costs you wish to record for yourself, before recording the full details in the correct place.

We will only be transferring relevant details from these sections, so we are happy for you to use these pages in any way that helps you.

Ethics

- University of Tasmania Human Research Ethics Committee (approval H0014183).
- The AMSLS Information Sheet can be downloaded from www.msaustralia.org.au/AMSLS

Need help?

For support, any questions or concerns please contact the AMSLS team:

(03) 6226 4739

AMSLS.info@utas.edu.au

When you are ready to return your *Cost Diary,* please use the Reply-Paid envelope provided or send to:

Menzies Institute for Medical Research
University of Tasmania
Australian MS Longitudinal Study
Reply Paid 77465
HOBART TAS 7000