

UNIVERSITY of TASMANIA

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Institute for Medical Research

2024 Economic Impact Study – The Cost Diary QuickStart Guide

What to record over the next 6-months

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.

Include everything from MS symptom management to preventative measures aimed at maintaining your overall wellbeing, whether you personally pay for them or not.

Key details to keep in mind:

- 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. Estimates are fine!
- If you're unsure about a cost, record it anyway: We know it's often hard to separate MS from other causes, or that activities may be aimed at improving your overall wellbeing and not specifically MS. Just add a note of explanation if you're in doubt and let us decide.
- **Please record <u>all</u> medications and supplements:** All medications and supplements can impact your overall wellbeing, so please record all of them.
- **Record barcodes whenever possible for MS related 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. See section 2.2 Transport in the Help Booklet if you would like further information.
- Take time up front to think of a suitable plan to record your costs and set yourself *Cost Diary* reminders <u>now</u>: The best routine to record your costs will depend highly on the number of costs you are likely to have, your lifestyle and your preferences. We encourage you to adopt whatever method you feel most confident with (if you would like some ideas, page 2 of the *Cost Diary Help Booklet* has a few suggestions). We do request, however, that you take time <u>now</u> to make sure your plan will practically work for your lifestyle and set regular electronic or physical reminders in your calendar. We recognize the *Cost Diary* will become a lower priority in the flow of everyday life, so setting a plan in place so you can avoid becoming overwhelmed with too many costs to transfer, or forgetting costs entirely will be vital for completion.

Getting assistance:

The <u>Cost Diary: Help Booklet</u> provided contains more detailed explanations, instructions and completed examples of scenarios that may arise as you start recording costs. An electronic copy is also available on the MS Australia website if you lose your physical copy or would like to use a key word search (www.msaustralia.org.au/AMSLS/current-surveys/).

If you have any other questions, please reach out to us. We are happy to assist in any way we can!

Cost Diary QuickStart Guide

Category descriptions and example items

Below is a guide to where costs should be recorded, including examples of common costs in each category. Please remember the lists are not exhaustive, and it doesn't matter if you make a mistake, or put a cost in the wrong place. We can always contact you for clarification.

SECTION A: YOUR REGULAR COSTS

For your recurring weekly, fortnightly, or monthly costs that form part of your routine during the 6-months of the *Cost Diary*. These are costs you could budget for, even if the exact day they occur may vary slightly.

Category	Page(s)	Examples
NDIS and My Aged Care packages	3 – 4	 Details and updates of any National Disability Insurance Scheme or My Aged Care funding you receive
Memberships, subscriptions and travel cards * includes any transport required	5 – 10	 Gym, pool, club or society memberships Subscription based services (e.g. Noom, Calm, Headspace, Aaptiv, Sleep Cycle, Dinnerly, HelloFresh) Time-based travel cards (Myki Pass, Opal, Translink, Metro, Transperth, MyWay) and long-term parking spaces
Regular services and appointments * includes any transport required	11 – 16	 Regular cleaning services Regular gardening services Regular physio or rehab
Regular transport * if adjusted to accommodate MS	17 – 20	 Regular travel to work Regular / routine travel for shopping and social outings

SECTION B: HOUSING AND LONG-TERM ASSETS

For your structural car and house costs, and any other equipment you have bought or hired in the past 5 years for your MS that can reasonably be expected to have a longer life span (3 years or more).

Category	Page(s)	Examples
Private car costs * excluding running costs		 Alterations to your private vehicle (car controls, adjustments to fit mobility aids, assistive equipment to get in and out) Purchases of a more suitable private vehicle
Housing costs	25 25	 Full time nursing home residency Minor installations (air conditioners, grab rails, blinds, ramps) Major renovations to the structure of your property Moving, house purchases and sales
Pre-existing special equipment purchased or hired in the past 5 years	27 – 29	 Mobility items (wheelchairs, walking frames, scooters, hoists) Medical equipment (TENS machines, pumps, monitors, watches) Exercise equipment (bikes, weights, treadmills) Visual aids (glasses, magnifiers, lights, sunglasses) Communication aids (computers, hearing aids, phones, safety monitors) Household items (all aid equipment (non-slip, commodes, electric toothbrushes, kitchen aids, trolleys), taps, furniture, cushions, fans) Clothing (medical stockings, temperature control items, shoes) Maintenance costs for any of the above (batteries, tyres, repairs)

Contact the AMSLS team: (03) 6226 4739 AMSLS.info@utas.edu.au

** Please use barcodes for purchases wherever possible **

** Even if multiple different MS costs are incurred on a trip, only record one transport entry **

SECTION C: PURCHASES

For any physical items you buy or hire to assist with your MS during the 6-months of the Cost Diary period.

Category	Page(s)	Examples
C1: Medications and supplements * regardless of linkage to MS	31 - 38	 <u>ALL</u> tablets, capsules, liquids, gels, patches, creams, ointments, inhalers, sprays, powders, lozenges, drops
C2: New item purchases and equipment hiring * during the 6-months of the Cost Diary	39 – 44	 Any items listed in Section B's Pre-existing Special Equipment Disposable equipment and items (containers, bottles, dressings, gloves, bags, lubricants, cleaning products, wipes, suppositories) Continence items (diapers, pads, liners, pants, catheters, mattress/furniture protectors)

SECTION D: SERVICE USAGE AND TRANSPORT

For all your appointments, assistance and advice received, and irregular or once off transport during the 6-months of the *Cost Diary* period.

Category	Page(s)	Examples
D1: Appointments and other services	45 - 58	 Health professional appointments (including all allied health professionals and pre-planned hospital day procedures) Assistance services (cleaning, gardening, personal assistance, trades) Support services (MS societies, social workers, banks, NDIS case managers) Exercise and movement services and usage (pools, gyms, spas, saunas, exercise/relaxation/strength classes)
D2: Medical tests and scans	59 – 68	 Blood tests MRIs EEG Eyes/optical tests Ultrasounds Urine/stool tests X-Rays Urodynamics Liver function
D3: Additional transport	69 - 76	 Any transport not recorded elsewhere
D4: Temporary hospital and health care admissions	77 – 80	 All hospital admissions (operations, accident and emergency attendance, other overnight and longer admissions) Rehabilitation admissions Hospital in the home Respite care

SECTION E: NOTES AND COMMENTS

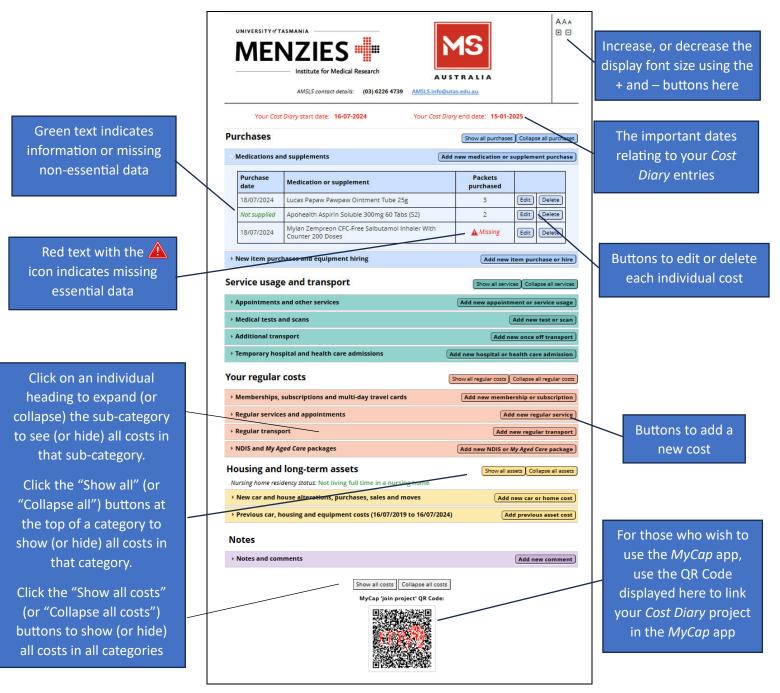
For any additional information, comments, questions or details you would like to provide.

The browser-based Cost Diary

When you first start the *Cost Diary*, you will be guided through the costs for *Section A* (related to your regular costs) and *Section B* (any housing or other long-term assets you have purchased over the past 5 years). These are costs that have either already occurred, or form part of your current routine.

It is important to note that it is **not** essential that these costs are entered in full upfront. Once you have completed the setup, you will be presented with your main *Cost Diary* page (below) where you can add, edit and delete costs from all categories throughout the 6-months of the *Cost Diary* period.

Please note that while the *Cost Diary* is functional on phones, for ease of use we recommend that you use a larger screen (tablet, laptop or desktop) when using the browser-based *Cost Diary*.





MyCap 4+ Vanderbilt University Medical Center

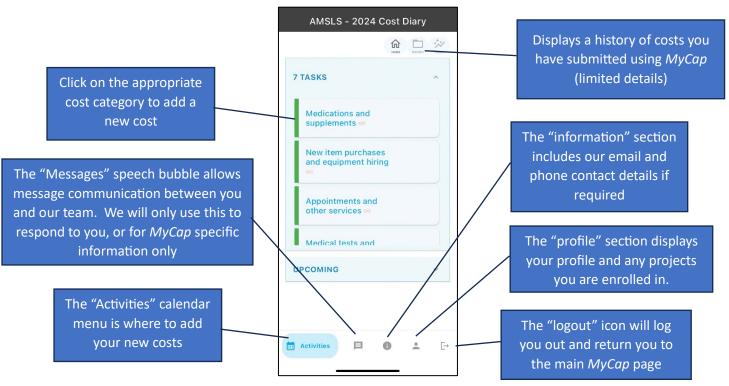
The MyCap app

Free

The *MyCap* app provides an option for those who would like a quick, easily accessible app on their phone to add new once-off costs from Sections C and D) on the go. In particular, the *MyCap* app provides barcode scanning via your phone's camera, which helps reduce manual input for many purchases.

How to download and link the MyCap app to record your one-off costs

- 1. Complete your *Cost Diary* setup on your chosen web browser.
- Install the purple *MyCap* app on your mobile device (iOS: <u>App Store</u>, Android: <u>Play Store</u>).
 *Note: <u>Not</u> the black "MyCap Classic" app.
- 3. Once installed, open the *MyCap* app and create your profile, including a username and 6-digit passcode of your choice. **Note: The username and passcode you choose are for your privacy only and are <u>not</u> linked to the AMSLS. We strongly recommend using a passcode you will remember, as we cannot reset it.*
- 4. Once your profile has been created, open it and tap the "Join Project" button on the bottom of the screen.
- 5. When prompted, scan your QR code displayed on the *Cost Diary* 'setup completion' page, or the bottom of your web-based *Cost Diary* homepage. The app will ask you if you want to allow push notifications; These are <u>not</u> necessary for the AMSLS *Cost Diary*.
- 6. When you open the *Cost Diary* project, use the "Activities" tab (calendar icon) at the bottom to add costs.



Important notes on the MyCap app:

The *MyCap* app is **not** required to complete the *2024 Cost Diary*, but is available to those who would find it convenient. Importantly, *MyCap* can only add new once off costs, and any editing or viewing of your saved costs, or updates to regular costs and long-term assets **must** be done on the browser-based version.

if you do have the browser-based *Cost Diary* open when entering new costs via the *MyCap* app, don't forget to refresh/reload your browser *Cost Diary* in order to see the new *MyCap* costs.

Ethics

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

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