

Dr Raymond J Mullins

MB BS, PhD, FRACP, FRCPA

Consultant Physician, Clinical Immunology and Allergy

Suite 1, John James Medical Centre, 175 Strickland Crescent, Deakin ACT 2600.

Tel 02-6282 2689; Fax 02-6282 2526 Educational Website <http://www.allergycapital.com.au>

Patient Instructions for ONGOING Immunotherapy INJECTIONS & TABLETS

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Recap on immunotherapy methods

Immunotherapy involves regular exposure of commercial extracts of allergen protein, with the aim of switching off the allergic response. The options are:

- Grass and dust mite tablets -very good products, high quality research studies, fully registered, on prescription, effective but expensive.
- Cat tablets – expensive, small studies, imported for your use but okay rather than great.
- Oral liquid - expensive but okay rather than great.
- Traditional injections - separate injections for each allergen, and more hassle with weekly doses for a few months, then monthly. 70 years of experience and usually work.
- Newer allergoid injections - safer, less injections, can mix into 1 bottle and often cheaper BUT there is no evidence that these *are as good* as the traditional injection method, as there are no comparative studies.

Has it worked?

If you have found treatment to be effective, the best advice is to **continue** maintenance immunotherapy tablets or injections for at least 3 years, sometimes up to 5 years. Follow-up studies are now showing long-term benefit many years after stopping, at least 7 years from grasses and at least 3 years (studies so far) for dust mite immunotherapy.

Medication can be used as well

Unfortunately, there is no treatment that is 100% effective for 100% of people. As a rough rule of thumb, 65-75 % of people benefit and their symptoms are reduced by around 65-75 %. So you can still use medications if you wish.

Allergen storage

Tablets are stored at room temperature. Injectable extracts should be refrigerated but not frozen. They will be fine if stored at room temperature by mistake for a few days but need to be replaced if they are frozen.

Side effects

Don't forget; an antihistamine a few hours before the injections reduces side effects and increases safety. I always tell people to take antihistamines for the first few weeks or oral tablets as well, for the same reason.

Using expired injectable extracts

Every now and again, people forget to order more allergen and run out, or there are unexpected gaps so that allergen is still left in the bottle but the expiry date has passed. Don't get too worried. An expired extract may be slightly less potent but will still be effective many months after the expiry date. So keep using the old expired allergen, but ordered more and swap over when the new bottles arrive.

Review appointments

I usually see people to start immunotherapy, then 6-7 months later for review. If you are doing well, I will discharge you back to your GP for ongoing care. I only need to see you if problems arise or there are major gaps between doses. If you do need to return, you will need a current/new referral from your GP once your old one runs out. Check when you ring in.

TABLETS: Getting more supplies

ANY doctor can write prescriptions for immunotherapy tablets if you run out, lose the script or if I am away or unavailable. Acarizax dust mite tablets and Grazax grass tablets come in boxes of 30 or 90/time. Oralair grass tablets and Actair dust mite tablets come as an initiation script when starting (3+28), and then as maintenance script (boxes of 30 or 90). If you do well on the tablets, then I will *discharge you back to your GP for ongoing scripts* and Oralair restart appointments mid-year. You *do not need* to restart with me each year and do not need to see me again if doing well.

INJECTIONS: Getting more supplies for a 9-10 months cycle

As it takes up to 2-3 months to obtain more allergen from Europe, you need to always think that far ahead! Each bottle contains enough liquid for 4-5 injections/4-5 months. Thus in most cases it is probably better to order 2 maintenance bottle/time = 9-10 injections = 9-10 months supply (ALK brand) or ~12 months supply (Diater brand). When you finish the first bottle (leaving 1 bottle left) you order another 2 bottles so you always end up having 10-12 months supply in the fridge. Put this on your calendar and in your diary so you don't forget. *BUT- the original order form you were given does authorise 6 repeats!* So if you have forgotten to return for review (and to get new paperwork and order forms), and you run out, you already have a valid order form to order more. Just change the delivery address to your GP, NOT DR Mullins! If for some reason you need more order forms and I am unavailable, your GP can complete the order form by contacting the drug company and getting copies of their order forms.

Repeat order forms ("paperwork") for injectable allergen

I have given you a prescription for allergen that contains multiple repeats, so you should be able to continue to use this for several years to come. Just photocopy the order form and re-use. But you can also use your original order form, and your GP can contact the drug companies and obtain their order forms and complete these for you too. *Don't lose the paperwork - I charge a fee to do these again unless you have an appointment at the time.*

Check injectable allergen bottle delivery

Check your credit card statement and check that the 2 bottles have arrived. They will be packaged in separate white boxes (ALK brand) or 1 orange box (Diater brand) with your name on them. Consolidate the bottles into the **ONE** box to make it easier to keep an eye on your supplies.

Note: Injection frequency If you have the injections every 4 weeks, you will end up having 13 injections/year, and run out of allergen a month earlier than you expected! The Administration sheet for your doctor also gives you a warning, as long as you keep an eye on it.

Ongoing administration forms for injections

I always post your GP at least 2 copies and give you a backup copy too in case the GP loses it or scans it into their computer system and can't find a hard copy. If the GP cannot find their copy, tell them to check they have not scanned it into their system or give them a copy of your backup sheet. That saves a lot of time & trouble for all involved. But in reality, it is only a piece of paper. Apart from a 20% reduction in dose when starting a new bottle, the dose does not change. As long as you order more injections when you have finished your first bottle, you should be fine.

I stopped immunotherapy by mistake; what do I do?

TABLETS: just restart with your GP. For some brands like Oralair and Actair, you will need a script from the GP for an initiation pack (3+28).

INJECTIONS: Just dig up the old paperwork and follow the restart protocol (lower dose first) and keep going. If you have run out of allergen, just order more and use the old paperwork. You do not need more pieces of paper from me.

If it used to work and now it doesn't...

If your symptoms start to return while on immunotherapy tablets or injections, even though it used to help quite well, there are 2 things to consider. The first is that you have developed a new allergic trigger (uncommon but possible) or are now exposed to a new allergic trigger (eg. You bought a pet). The second is that you have a second problem, like nasal polyps or sinus infection. I recommend returning for review.

What if it does not work at all?

There are a few options:

1. Continue more of the same for longer; immunotherapy is usually better in the 2nd year than the first.
2. Change method. Eg. Injections to tablets or vice versa, or allergoid (less hassle) injections to the traditional method.
3. Add vitamin D tablets to immunotherapy. There are studies showing that people with low vitamin D are less likely to respond to immunotherapy and that supplements can improve effectiveness.
4. Consider whether there is another problem that has developed. Eg. A new allergy, sinus infection, nasal polyps.

